Growing Up in New Zealand

Now We Are Twelve

Life in early adolescence

# Supplementary Material for *Now We Are 12:* The impact of disability on young people and their family

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## 1. Introduction

Summary of the *Growing Up in New Zealand* study and 12-year data collection wave including collection, methodology and cohort description can be found in the Introduction & Methodology reports.

## 2. What do we know about disability?

The New Zealand (NZ) Government has a vision for NZ to be a non-disabling society "where disabled people have an equal opportunity to achieve their goals and aspirations" (p.6) (1). The NZ Disability Strategy (1) outlines outcomes in relation to different areas of importance to disabled people, including equitable access to and attainment of high standards in education, economic security, and health and wellbeing. During the 12-year data collection wave (DCW), *Growing Up in New Zealand* (*GUiNZ*) set out to gather data on disability that highlights the factors affecting progress towards achieving these outcomes.

The New Zealand Office for Disability Issues (ODI) works within the social model of disability whereby people are not inherently disabled because of individual impairments, rather, the barriers they face within society mean that they are highly likely to be faced with disabling experiences (1). This aligns with the United Nations Convention on the Rights of Persons with Disabilities (the Convention) (2) which states that disabled people are "…those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others…" (p.4). The 2013 New Zealand Disability Survey (3) estimates that the disability prevalence rate for children and young people under 15 years was approximately 11% (15% for rangatahi Māori).

To ensure we reflect the voices of young people and their whānau, we have taken an inclusive and holistic measurement approach, utilising both young person self-report and parent/main caregiver report of functional areas of concern.

Although we did not ask explicitly whether young people identified themselves as "disabled", focusing on functional impairment means that analyses can look at outcomes for young people at risk of disablement. Accordingly, *GUiNZ* has reported on disability using a combination of two measures: the young person self-reported Washington Group Short Set on Functioning (WG-SS) (4) and a set of questions answered by the young person's parent or main caregiver based on the Washington Group/UNICEF Child Functioning Module (CFM) (5) (for additional information on measures used see Appendix 1).

This report uses the term “disabled young person” when describing this cohort of young New Zealanders, which includes young people with any of the following:

- **Self-reported difficulties** (cannot do at all or has significant difficulty) with seeing, hearing, walking, climbing stairs, remembering, concentrating, self-care (such as washing and dressing), and/or communicating.
- **Parent/main caregiver** reported difficulties (cannot do at all or has significant difficulty) with self-care, communication, learning new things, remembering, concentrating, accepting change to their routine and/or controlling their behaviour.
- Learning support needs/disability because of a hearing, vision and/or physical impairment (as reported by a **parent/main caregiver**).
- A doctor’s diagnosis of depression and/or anxiety at any time in their life (as reported by a **parent/main caregiver**).

Where the analysis is related to educational outcomes the definition of disability included young people whose parents/main caregiver reported that the young person had an additional learning need (i.e., a specific learning disability, autism, or intellectual disability, see Appendix 1 for details).

Our family-centred approach to disability focuses on the impact that having a disabled young person and/or parent has on the family unit (for more details see Appendix 1). The family disability variable forms three distinct categories – no disability within the family, families where the participant young person has a disability (as defined above), and families in which a parent or parents have a long-term disability (the cohort young person may or may not have a disability also). Note, we did not ask about sibling or extended family disability in this DCW.

This multi-pronged approach has allowed us to highlight the impact of disability on the family unit and assess potential effects on the young person’s life. To help us share the voices of participants, we have included their words as comments throughout the report.

For greater insight into the 12-year DCW, see the Introduction, Methods, and Now We Are Twelve reports.

## 3. What can *Growing Up in New Zealand* add?

*Growing Up in New Zealand* has a unique opportunity to examine disability using a combination of parent and young person viewpoints that provide a deeper understanding at both the individual and family level. *GUiNZ* can also look at disability from a household perspective, which historically has not been routinely collected in national surveys or administrative data.

## 4. Research questions and objectives

**Research question 1**: Disability at the individual level - What proportion of young people are experiencing disability at the 12-year DCW?

Objectives:

1. To describe the proportion of 12-year-olds who self-report having a disability according to the WG-SS scale.
2. To compare young people identified as disabled via the WG-SS (which uses a self-report method) to those identified as disabled via a question set based on the CFM answered by their parent, and to young people with learning needs.
3. To assess these different definitions of disability within the cohort and investigate potential differences in wellbeing and school outcomes.

**Research question 2**: Disability at the family level - What proportion of young people and parents are experiencing disability at the 12-year DCW?

Objectives:

1. To derive and describe disability in a family setting by including mother, partner, and young person at the 12-year DCW.
2. To describe family disability by household and economic factors such as rurality, tenure, crowding, mobility, income, deprivation, and material hardship, both at the 12-year DCW and across time.

## 5. Key findings on disability from the 12-year interviews

- There was a large difference in those identified as disabled when using the WG-SS (young person self-report) vs. the CFM-based questions (parent-report) with less than 20% of young people being identified as disabled by both sets of questions.
- Self-reported disability differed across the cohort by gender, ethnic group, and area level deprivation.
  - The proportion of young people who reported disability was greater amongst transgender, non-binary or ‘unsure’ of their gender young people than cisgender boys or cisgender girls.

  - The proportion of self-reported disability was greater in Māori and Pacific ethnic groupings than in the sole European group.
  - A greater proportion of disabled young people lived in areas of high deprivation.
- Disabled young people reported:
  - Lower health-related quality of life.
  - Higher scores for depression and anxiety.
  - Poorer relationships with peers and parents.
  - Feeling less safe in their neighbourhood.
  - Lower school engagement scores.
- A greater proportion of families with disability:
  - Were in single-parent homes.
  - Had poorer housing quality.
  - Lived in rental accommodation.
  - Had experienced greater residential instability.
  - Had inequitable annual incomes.
  - Faced more material hardship over time.

> ***"I'm unique in my own way"***

> ***"I have my differences, I love having hearing aids because it makes me unique!"***

> ***"I'm unique and capable of doing lots of things"***

# 6. Disability findings

## 6.1. *Research question 1:* What proportion of young people are experiencing disability at the 12-year data collection wave (DCW)?

### — Objective 1 —

*To describe the proportion of 12-year-olds who self-report having a disability according to the WG-SS scale.*

In this section we use the young person self-report set of questions (Washington Group Short Set on Functioning (WG-SS), see Appendix 1; Section 1.1.1a for details on derivation of this variable) to identify disabled young people and then describe this group in further detail by gender and ethnic identity as well as by NZ Area Level Deprivation (NZDEP18). The WG-SS has not been designed for self-report in this age group and therefore application and interpretation of these findings should be done with caution, however as a child-centric study we have chosen to highlight the views of the young people. Details on the analytic sample used for these analyses can be found in Appendix 2.

At 12 years of age, 9.8% ($n$ = 437/4447) of young people self-reported functional impairment corresponding to individual disability. For more information on the 12-year cohort, see the Introduction, Methodology, and Who Are We reports.

Consistent with previous reports (6), there were a greater proportion (Pearson $X^2$=79.71, p<.0001) of disabled young people who were transgender, non-binary and unsure of their gender 18.8% ($n$ = 138/736, p<.0001) than for cisgender boys (7.8%, $n$ = 158/2037) or cisgender girls (8.4%, $n$ = 141/1674, Table 1 and Figure 1).

Table 1. Young person self-reported gender, by WG-SS disability ($n$ = 4447).

| | Cisgender Boy | Cisgender Girl | Transgender/Non-binary/Unsure | Total |
|---|---|---|---|---|
| **Disability** | 158 (7.8) | 141 (8.4) | 138 (18.8) | 437 (9.8) |
| **No disability** | 1879 (92.2) | 1533 (91.6) | 598 (81.2) | 4010 (90.2) |
| **Total** | 2037 (45.8) | 1674 (37.6) | 736 (16.6) | 4447 |

Note: Percentages in brackets (%). These are column percentages for gender by disability but row percentages for total across the cohort.

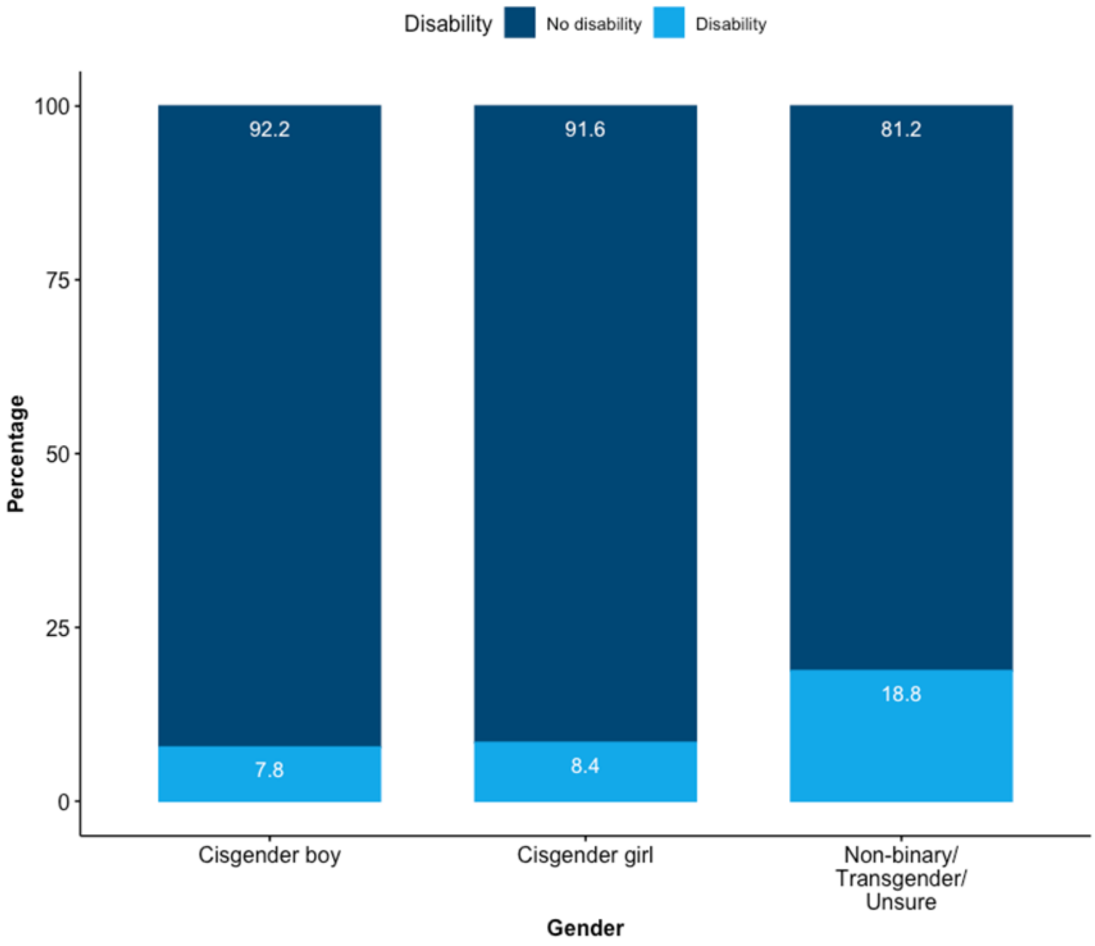


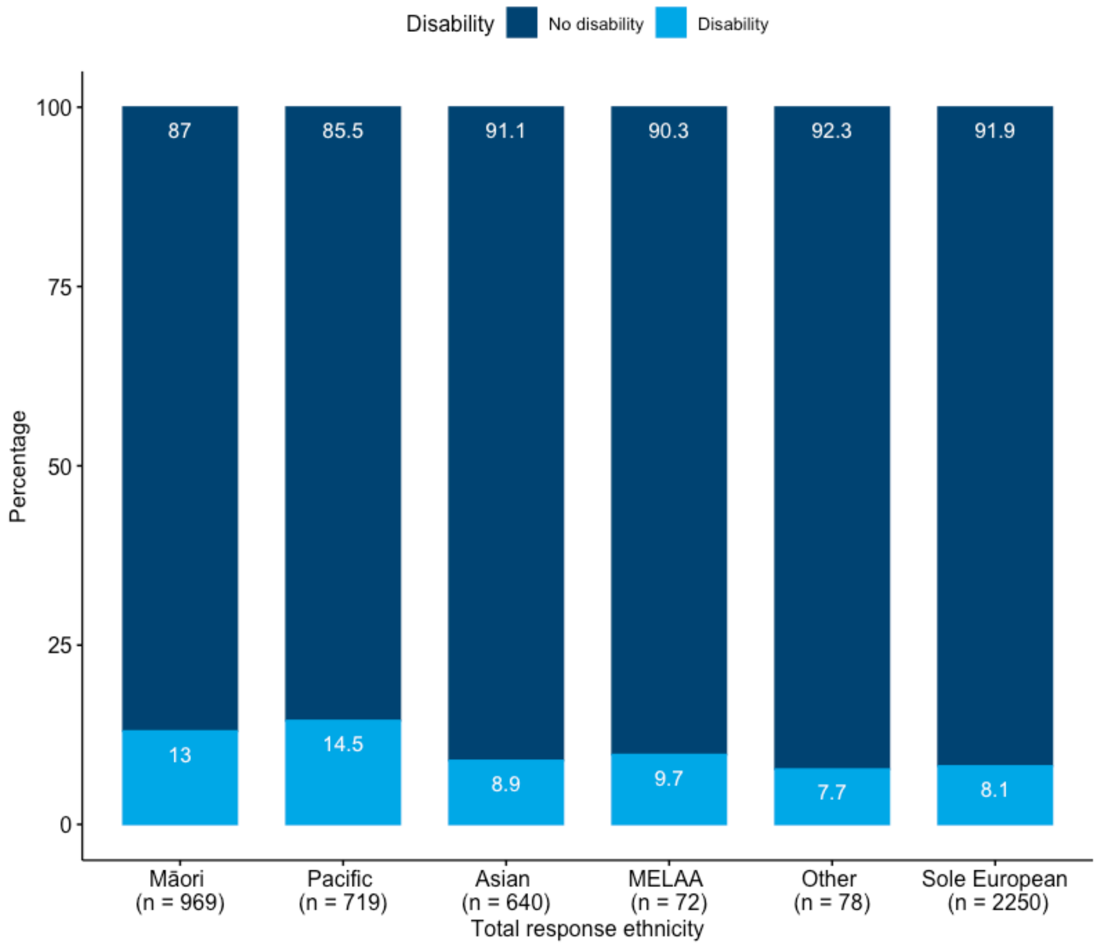
Figure 1. Young person self-reported gender, by WG-SS disability (*n* = 4447)

There were a larger proportion of both Māori (13.0%) and Pacific (14.5%) disabled young people compared to the sole European ethnic group (8.1%; Table 2 and Figure 2).

Table 2. Young person self-reported ethnic group, by WG-SS disability (*n* = 4333).

| | **Māori** | **Pacific** | **Asian** | **MELAA** | **Other** | **Sole European** | **Total** |
|---|---|---|---|---|---|---|---|
| **Disability** | 126 (13.0) | 104 (14.5) | 57 (8.9) | *n*<10 (9.7) | *n*<10 (7.7) | 183 (8.1) | 422 (9.7) |
| **No disability** | 843 (87.0) | 615 (85.5) | 583 (91.1) | 65 (90.3) | 72 (92.3) | 2067 (91.9) | 3911 (90.3) |
| **Total** | 969 (22.4) | 719 (16.6) | 640 (14.8) | 72 (1.7) | 78 (1.8) | 2250 (51.9) | 4333 |

Note: Percentages in brackets (%). These are column percentages for ethnicity by disability but row percentages for total ethnicity across the cohort. This is total response ethnicity therefore percentages will not add to 100%.



Note. Participants who reported more than one ethnic group are counted once in each group reported, except for the "Sole European" group, which includes only those young people who identified as European.

Figure 2. Young person self-reported ethnic group, by WG-SS disability (*n* = 4333)

Disabled young people were more likely to live in the most deprived areas of NZ; with a larger proportion of disabled young people living in quintile 5 (the highest level of deprivation, 15.4%) compared to young people living in households in less deprived quintiles (quintile 1 – 7.6%; Table 3 and Figure 3).

Table 3. Area level deprivation (NZDEP18) of household in which each young person lived, by self-reported WG-SS disability (*n* = 4362).

| | **1** | **2** | **3** | **4** | **5** | **Total** |
|---|---|---|---|---|---|---|
| **Disability** | 80 (7.6) | 87 (8.9) | 73 (8.6) | 70 (9.7) | 117 (15.4) | 427 (9.8) |
| **No disability** | 977 (92.4) | 889 (91.1) | 777 (91.4) | 649 (90.3) | 643 (84.6) | 3935 (90.2) |
| **Total** | 1057 (24.2) | 976 (22.4) | 850 (19.5) | 719 (16.5) | 760 (17.4) | 4362 |

Note: Percentages in brackets (%). These are column percentages for deprivation quintile by disability but row percentages for total deprivation across the cohort. A deprivation level of 1 indicates the least deprived areas, whereas a deprivation level of 5 indicates the most deprived areas.

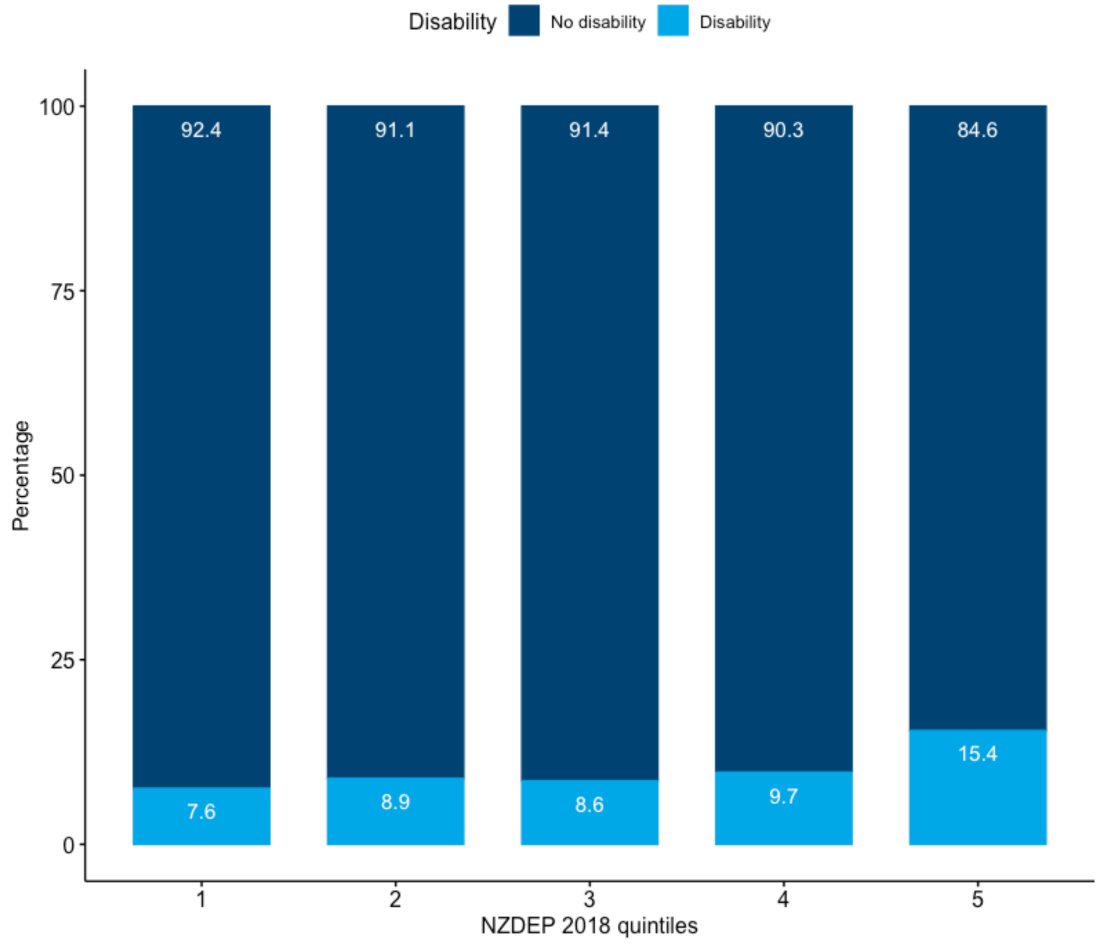


Figure 3. Area level deprivation (NZDEP18) of household in which each young person lived, by self-reported WG-SS disability ($n$ = 4362)

## — Objective 2 —

*To compare young people identified as disabled via the WG-SS (which uses a self-report method) to those identified as disabled via a question set based on the CFM answered by their parent, and to young people with learning needs.*

In this section we compare the results of the Washington Group Short Set (WG-SS) questions which were answered by the young people themselves (self-report) to the results of a set of questions based off the Washington Group Child Functioning Module (CFM) which were answered by their parents or main caregiver (parent-report) (see Appendix 1; Section 1.1.1b for details on how this was derived). Both sets of questions were used for identifying disabled young people. Finally, we identified young people with Learning support needs (see Appendix 1 Section 1.1.1c for further details on specific learning needs included) and looked for overlap with the self-reported WG-SS and/or the parent-reported questions based on the CFM. Details on the analytic sample used for these analyses can be found in Appendix 2.

When the young person self-report (WG-SS) was used as a measure of disability, 9.8% of participants are disabled (*n* = 437/4447). In contrast, the parent-report identified 12.4% (*n* = 529/4263) of participants as disabled.

When *GUiNZ* explored the results of these two sets of questions it was found that the groups identified as disabled by each were different. When looking at the young people identified as disabled by either set of questions, only 11.3% (*n* = 98/868) of them were identified as disabled by both.

Where data was available from both the CFM-based parent-report questions and the WG-SS young person self-report questions (*n* = 4228), *GUiNZ* found the following:

- When looking at young people who were classified as disabled based on the answers they gave about themselves, when answering the WG-SS, 76.0% (*n* = 311/409) were not classified as disabled based on their parent's answers to the CFM-based questions. (Figure 4).
- When looking at young people who were classified as disabled based on the answers their parents gave about them when answering the CFM-based questions, 81.1% (*n* = 422/520) of them were not found to be disabled based on their own answers to the WG-SS. (Figure 4).

It is important to note the question sets answered by the young people themselves differed to the questions answered by parents. See Appendix 1; Section 1.1.1a for the questions answered by the young people versus Section 1.1.1b to see the questions answered by parents.

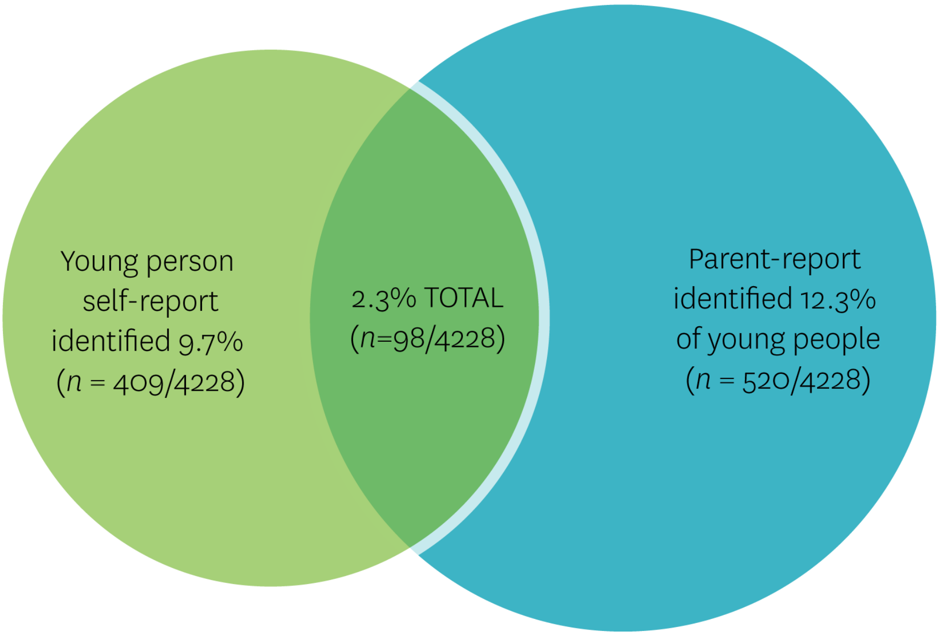


Figure 4. Venn diagram showing the incongruence between the WG-SS measure of disability and the CFM-based measure of disability

This means when we compared the two groups side-by-side those identified as disabled through each of the two measures, represented largely different groups of young people.

## Learning needs

When we included those young people, whose parents reported that they have learning support needs that may indicate a disability (see Appendix 1.1.1 for derivation), the proportion of the sample cohort identified as disabled increased to 24.5% (*n* = 1099/4482). Details on the analytic sample used for these analyses can be found in Appendix 2.

Figure 5 highlights the additional differences between the WG-SS (young person self-report), the CFM-based questions (parent-report) and those identified as having a Learning Support Need by their parents. Given some of the same questions were used for both CFM-based measure and Learning support needs the overlap between these groups is understandably higher (35.4%, *n* = 272/769). Note there were only *n* = 57 young people who were captured by all three measures of disability.

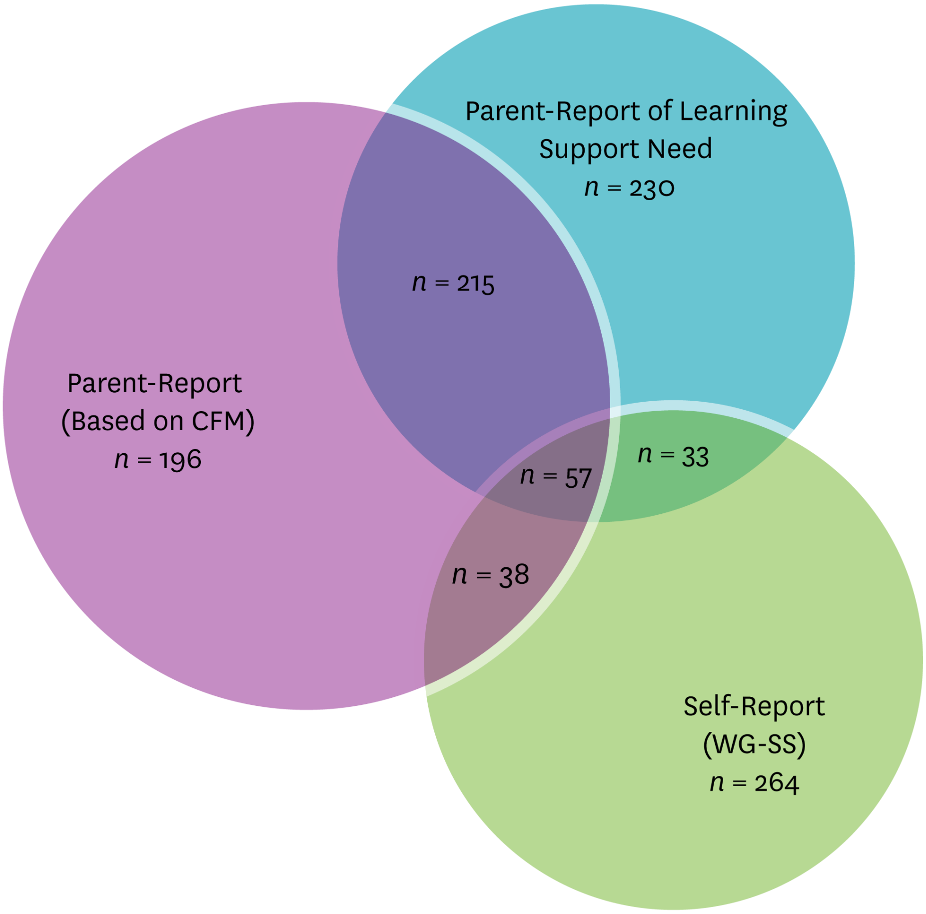


Figure 5. Venn diagram showing the differences between the CFM-based measure of disability, parent-report of learning needs, and self-reported WG-SS

***"I can be myself and no one will judge me"***

***"I feel like I am confident to just be who I want to be"***

***"I'll learn to be independent and look after myself and my family"***

## — Objective 3 —

*To assess these different definitions of disability within the cohort and investigate potential differences in wellbeing and school outcomes.*

This section describes the wellbeing of disabled young people at aged 12. For health and wellbeing, relationships, and sense of safety, we have included all young people who were identified as disabled either through the WG-SS (self-report) and/or by CFM-based questions (parent-report; 19.4%, *n* = 868/4482). For education outcomes, a disabled young person also included those identified as having an additional Learning Support Need that may indicate a disability (24.5%, *n* = 1099/4482). Details on the analytic sample used for these analyses can be found in Appendix 2.

## Health and wellbeing

The New Zealand Disability Strategy (1) highlights a need for disabled people to have equitable access to healthcare services, and healthcare services that are inclusive and responsive. This report found that New Zealand's general health and mental health outcomes are currently not equitable for disabled young people (at aged 12) compared to those with no disability.

### Quality of life

Young person-reported quality of life (using KIDSCREEN-10, see Appendix 3 for details) has been described using low, average, or high categories. Over half (53.6%) of disabled young people reported *low* quality of life (*n* = 465/868), which was a larger proportion than those with no disability (28.4%, *n* = 1026/3614; Pearson $X^2$=223.98, p<.0001; Figure 6.). In contrast, one third (32.7%, *n* = 1180/3614) of those with no disability reported *high* quality of life compared with only 14.2% (*n* = 123/868, p<.0001) of disabled young people.

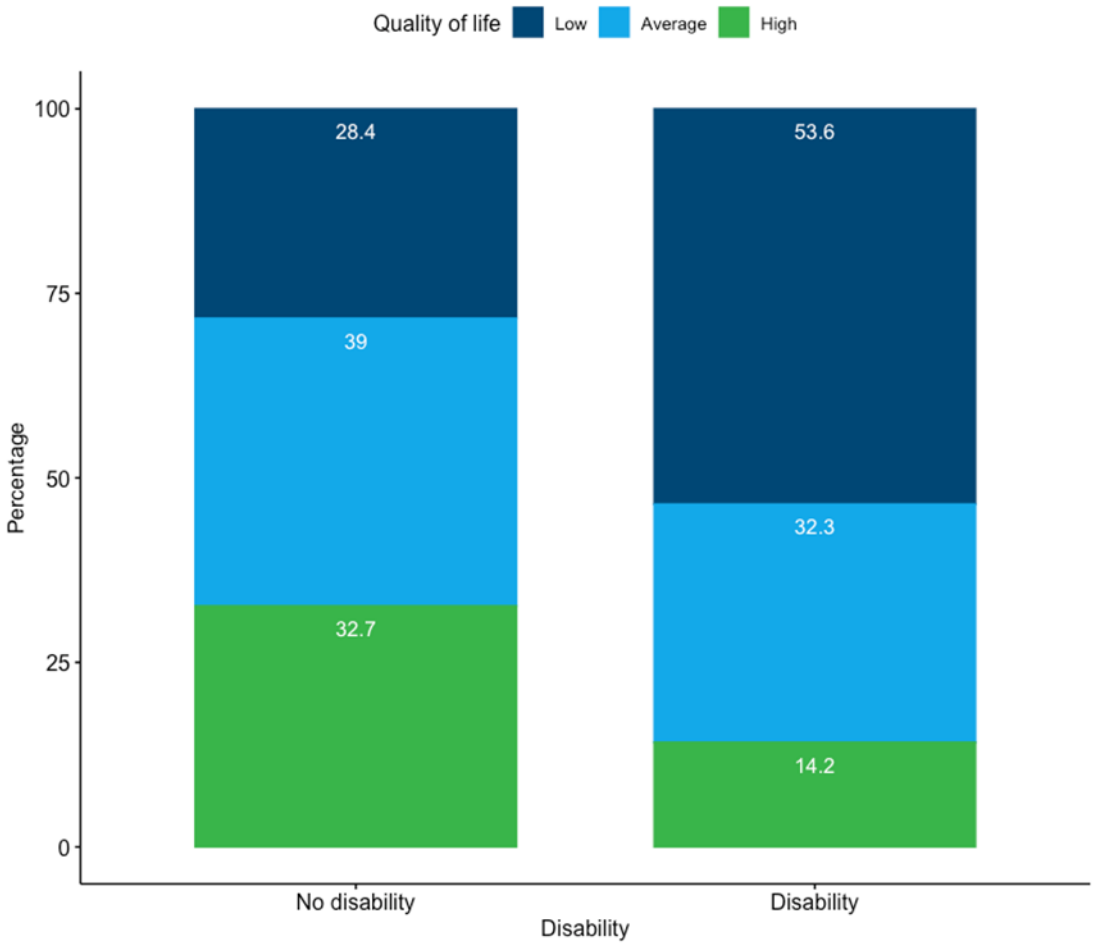


Figure 6. Quality of life using KIDSCREEN-10, by young person disability (*n* = 4482)

### General health status

The largest response category for disabled young people was for "good" health (39.4%), followed by "very good" health (32.9%). However, a greater proportion of people with no disability indicated that their general health was "excellent" or "very good" (68.4%) than disabled young people (47.0%; Figure 7). Additionally, a greater proportion of disabled young people indicated that their general health was "fair" or "poor" (13.5%) compared to just 5.6% of young people with no disability.

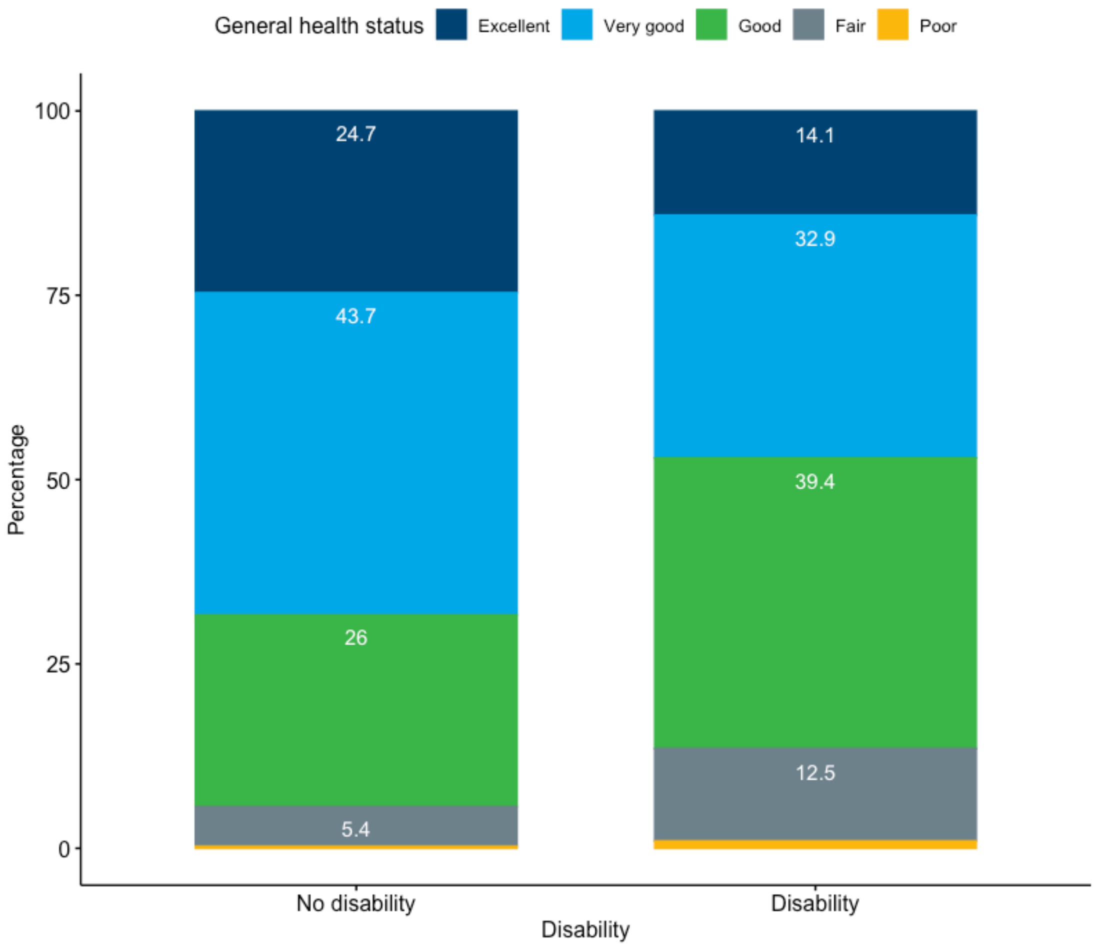


Figure 7. General health status of the sample cohort, by young person disability (*n* = 4354)

## Mental health status

Mental health was assessed using tools that ask about depression symptoms and symptoms of anxiety in the past seven days (see Mental Health report for details on both scores). Higher scores indicated a greater number of depression/anxiety symptoms. When measuring the impact of disability on symptoms of anxiety and depression, we removed those young people who had NOT have ever been diagnosed with anxiety or depression from the definition of “disabled” (*n* = 129).

Scores for depression were significantly higher for disabled young people (mean 11.54±SD 5.86, median 11.0) compared to young people with no disability (mean 7.90±SD 4.81, median 7.0; Welch’s F=248.04, p<.0001, Figure 8).

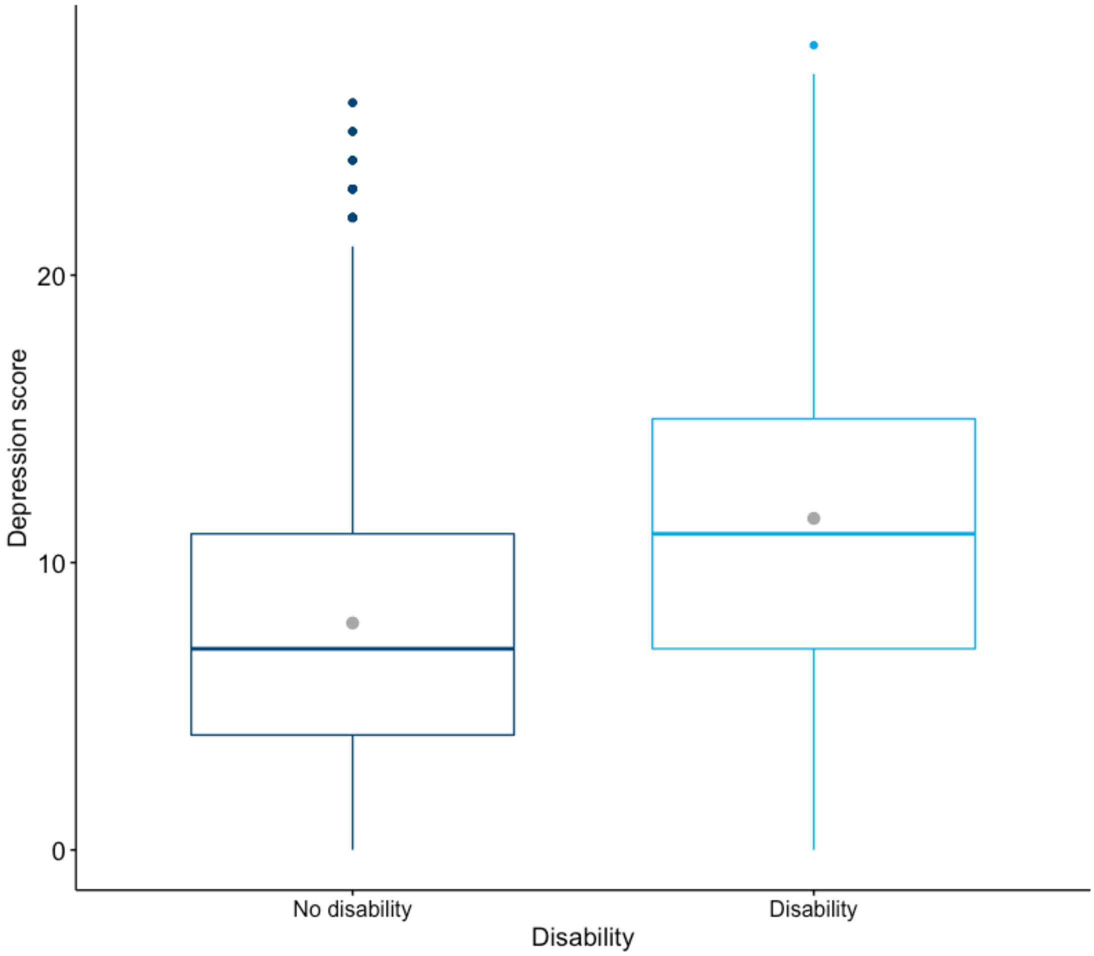


Figure 8. Depression score of the cohort, by young person disability (*n* = 4437)

A similar trend was seen for anxiety, with disabled young people having significantly higher scores (mean 50.07±SD 12.23, median 49.8) than young people with no disability (mean 45.24±SD 10.14, median 44.9; Welch's F=99.92, p<.0001; Figure 9).

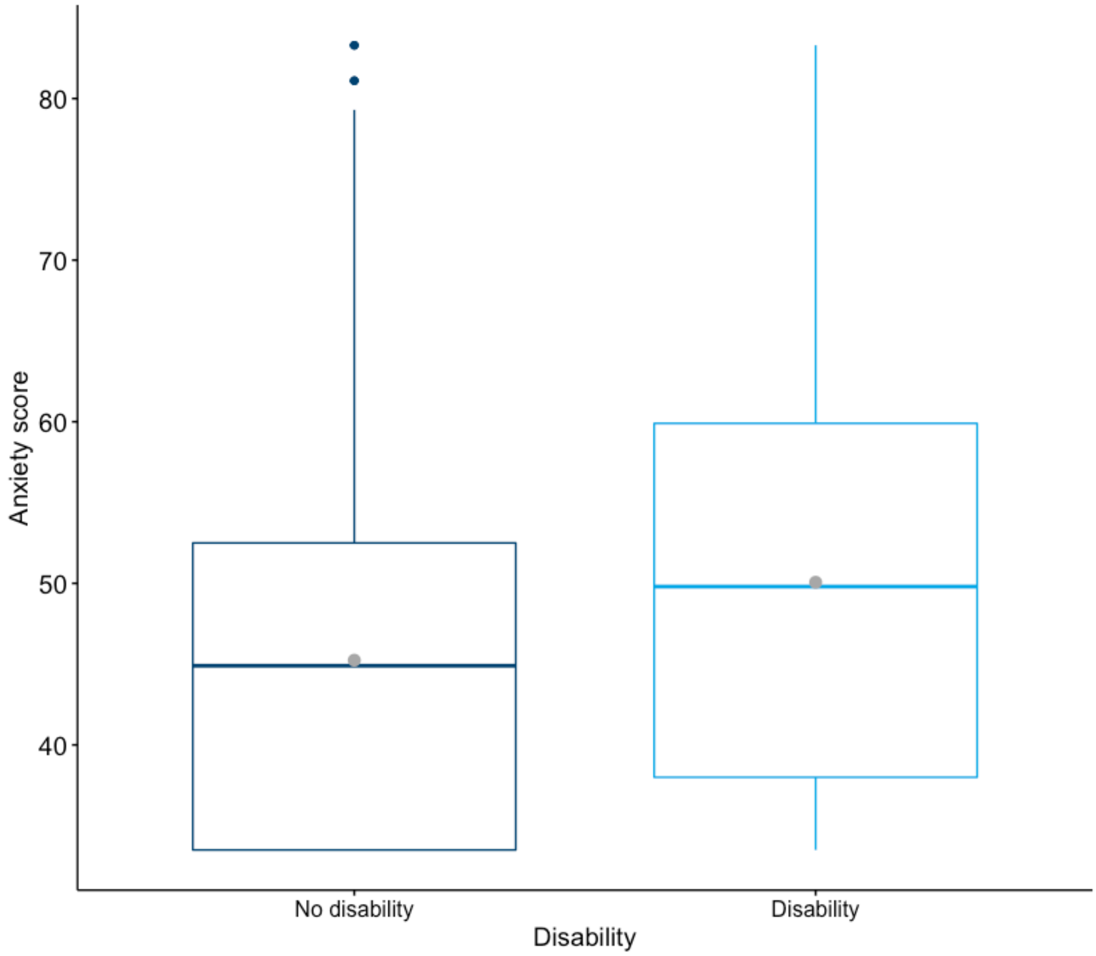


Figure 9. Anxiety score of the cohort, by young-person disability (*n* = 4437)

## Access to primary health care

To assess unmet need for primary care we asked parents if in the last 12 months, there had been any time when their young person needed to see a GP or family doctor about their health but did not get to see any doctor at all. When compared to those without a disability (5.5%, *n* = 186/3413), a larger proportion of disabled young people (9.3%, *n* = 78/837) reported that they had needed to see a GP or family doctor about their health in the past 12 months but did not get to see one.

A subsequent question asked for the **main** reason their young person was unable to see a GP. The most reasons for this were:

- Could not get an appointment soon enough or at a suitable time (disability – 52.6%, *n* = 41/78; no disability – 43.6%, *n* = 81/186)
- COVID-19 related reasons (disability – 15.4%, *n* = 12/78; no disability – 16.1%, *n* = 30/186)

Other reasons included cost, lack of transport, childcare, and time available to go to the doctors. However, these had too few responses to be reported. For more information on the impacts of COVID-19, see COVID-19 report.

## Meaningful relationships

The New Zealand Disability Strategy (1) states that, like people with no disability, disabled people will have relationships that are meaningful to them. The 12-year data collection wave (DCW) has evaluated relationships in several ways. In this report we have investigated both peer relationships and parent-child relationships, as well as an assessment of level of parental involvement in these young people's lives.

We found that disabled young people reported less trusting and communicative relationships with their peers and parents. For peer relationships, **higher** scores indicated **poorer** quality of relationships (see Relationships report for details on this scale). Scores for disabled young people (mean 18.02±SD 6.54, median 17.0) were significantly higher than for young people with no disability (mean 16.53±SD 5.98, median 16.0; Welch's F=29.47, p<.0001; Figure 10), indicative of less trusting and communicative relationships with their peers.

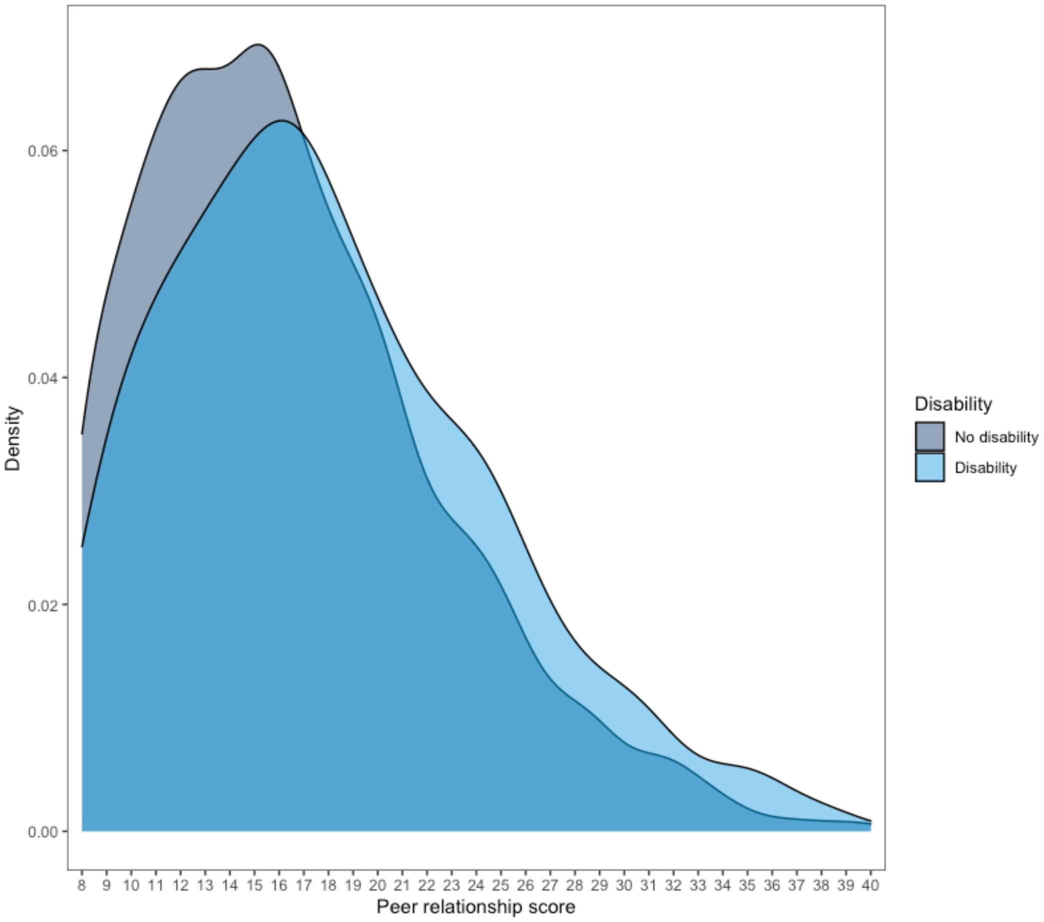


Figure 10. Peer relationships score of the cohort, by young person disability

Similarly, the parent-child relationships scale is interpreted with **higher** scores indicating **poorer** experiences of relationships (see Relationships report for details). Results showed that disabled young people (mean 14.0±SD 5.20, median 13.0) had significantly less trusting and communicative relationships with their parent/s than young people with no disability (mean 11.97±SD 4.22, median 11.0; Welch's F=102.35, p<.0001; Figure 11).

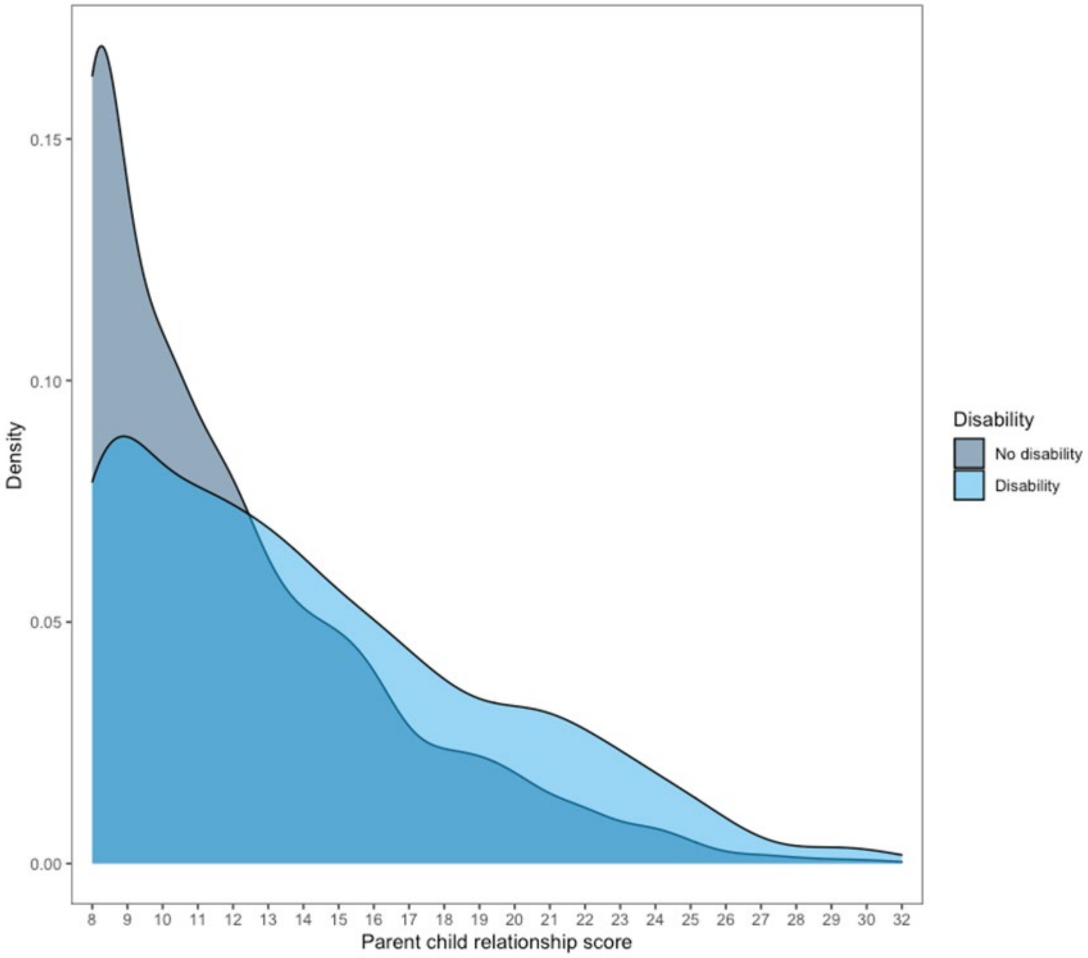


Figure 11. Parent-child relationship score of the cohort, by young person disability

Young people were asked about how they felt about the level of involvement their parents and caregivers had in their lives and if they would like to increase, keep the same, or decrease the level of parental involvement. Most young people thought their parent's level of involvement was about right, but this proportion was lower for disabled young people (49.7%, *n* = 427/860) compared to those without a disability (64.2%, *n* = 2306/3592). The proportion of young people who wanted a little or a lot less involvement was greater for disabled young people (7.9%, *n* = 68/860) than those young people with no disability (6.2%, *n* = 221/3592). Likewise, the proportion that wanted a little or a lot more parental involvement was also larger for disabled young people (30.7%, *n* = 264/860) than those young people without a disability (24.2%, *n* = 870/3592; Figure 12). These findings indicated that proportionately disabled young people were less content with parental involvement at both ends of the spectrum.

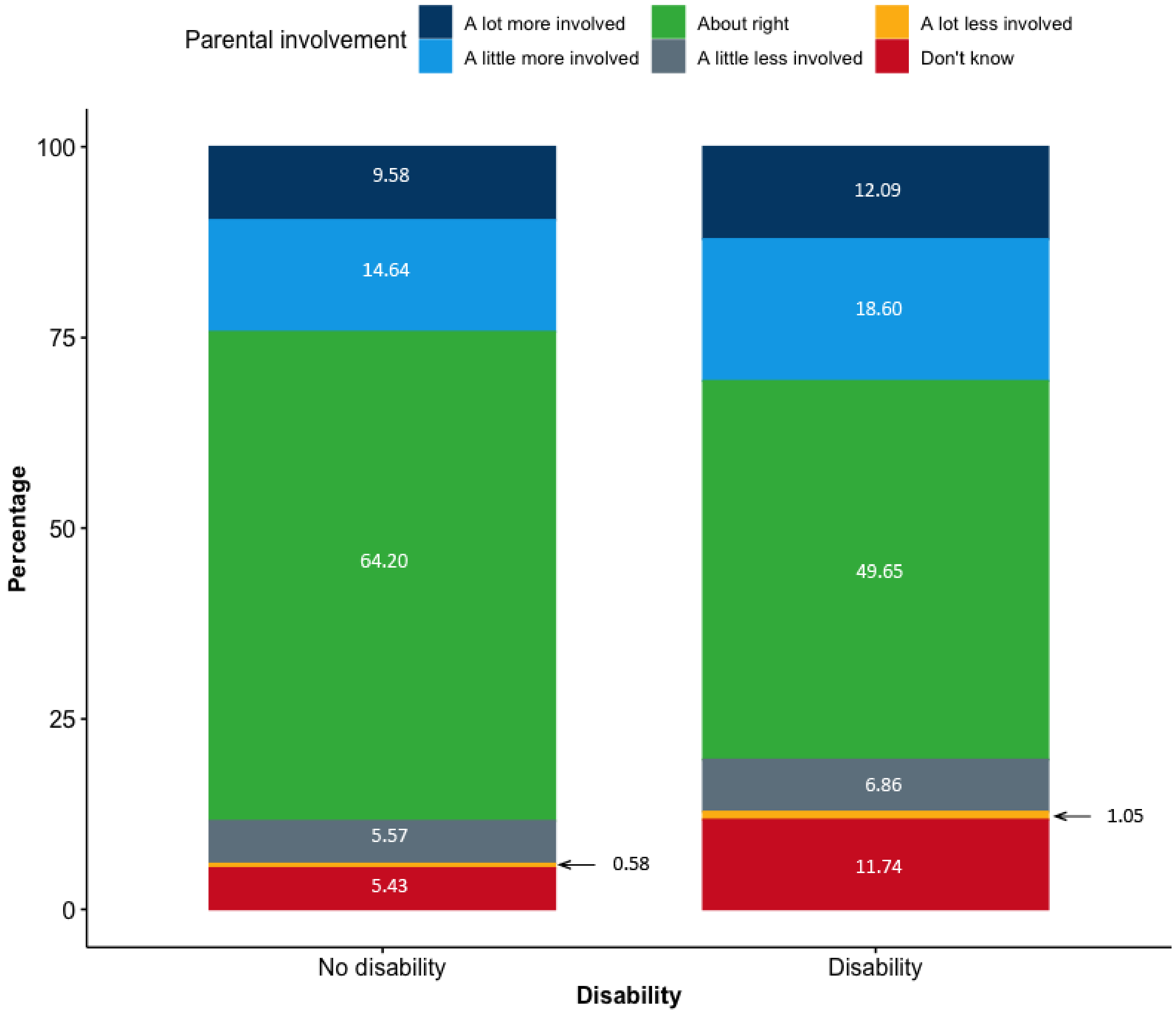


Figure 12. Parental involvement assessment, by young person disability

An additional question was asked **only** of those who wanted more parental involvement (*n* = 917) and explored what might be stopping their parents from being more involved. The most common response was due to their work (71.8%, *n* = 658), followed by being busy with other siblings (32.7%, *n* = 300), and then that they live too far away (10.4%, *n* = 95). The rest of the answers were below 10% and none of the answer options differed by disability.

### Sense of safety

Young people were asked how safe they felt in their neighbourhood, with answer options ranging from strongly agree to strongly disagree. Those pertinent to this report included:

- I feel safe walking and playing in the neighbourhood without an adult during the day.
- It is safe to walk around the neighbourhood at night.

Over two-thirds (68.5%, *n* = 582/850; Figure 13A) of young people with a disability agreed or strongly agreed it was safe to walk and play in their neighbourhood alone during the day; this proportion was greater for those young people with no disability (78.0%, *n* = 2784/3569). One-half of young people with no disability (51.7%, *n* = 1846/3569) agreed or strongly agreed it was safe to walk in their neighbourhood at night; this proportion was smaller for disabled young people (44.0%, *n* = 374/850; Figure 13B).

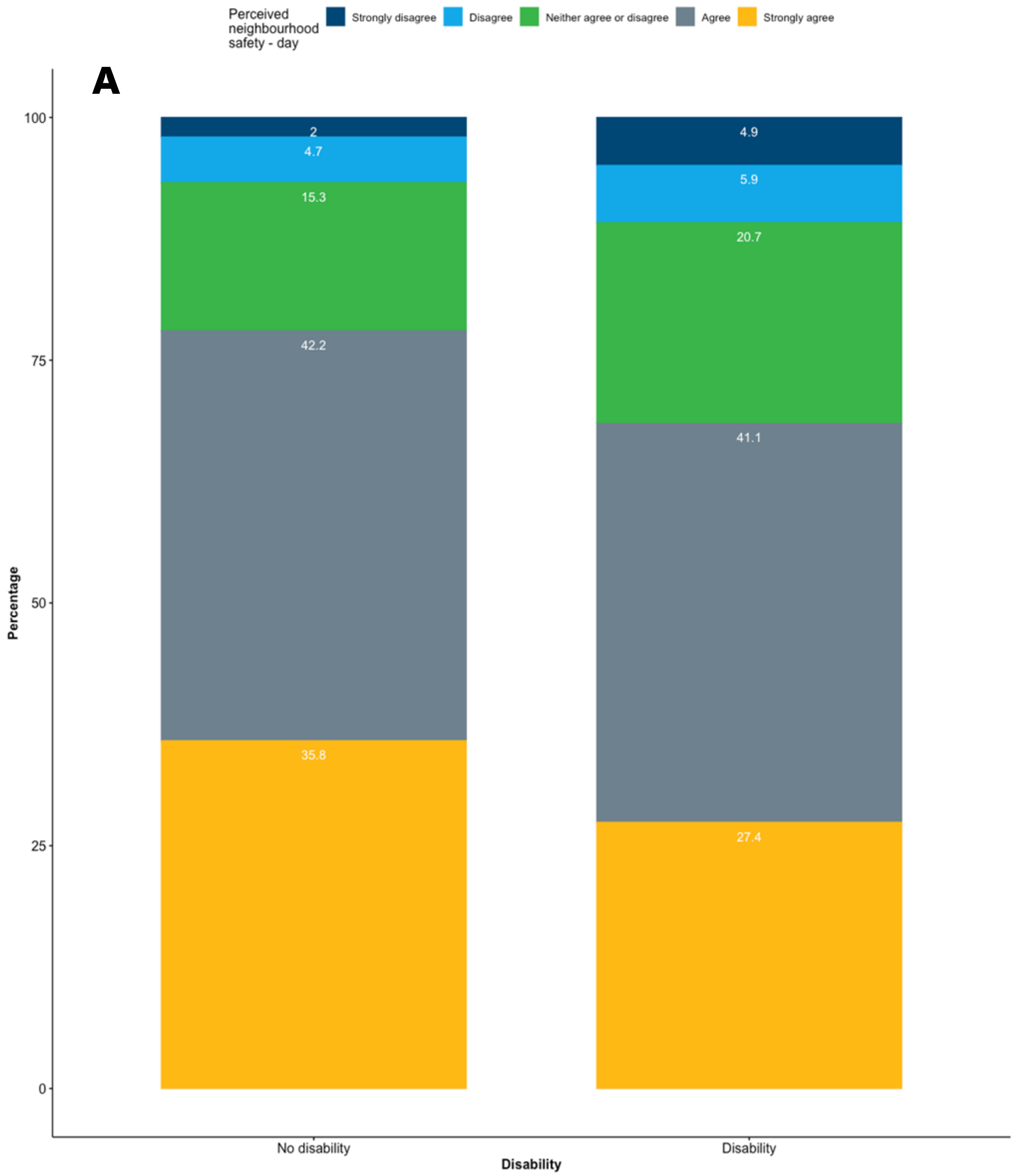


Figure 13A. Feeling safe walking and playing in their neighbourhood by day, by young person disability (*n* = 4419)

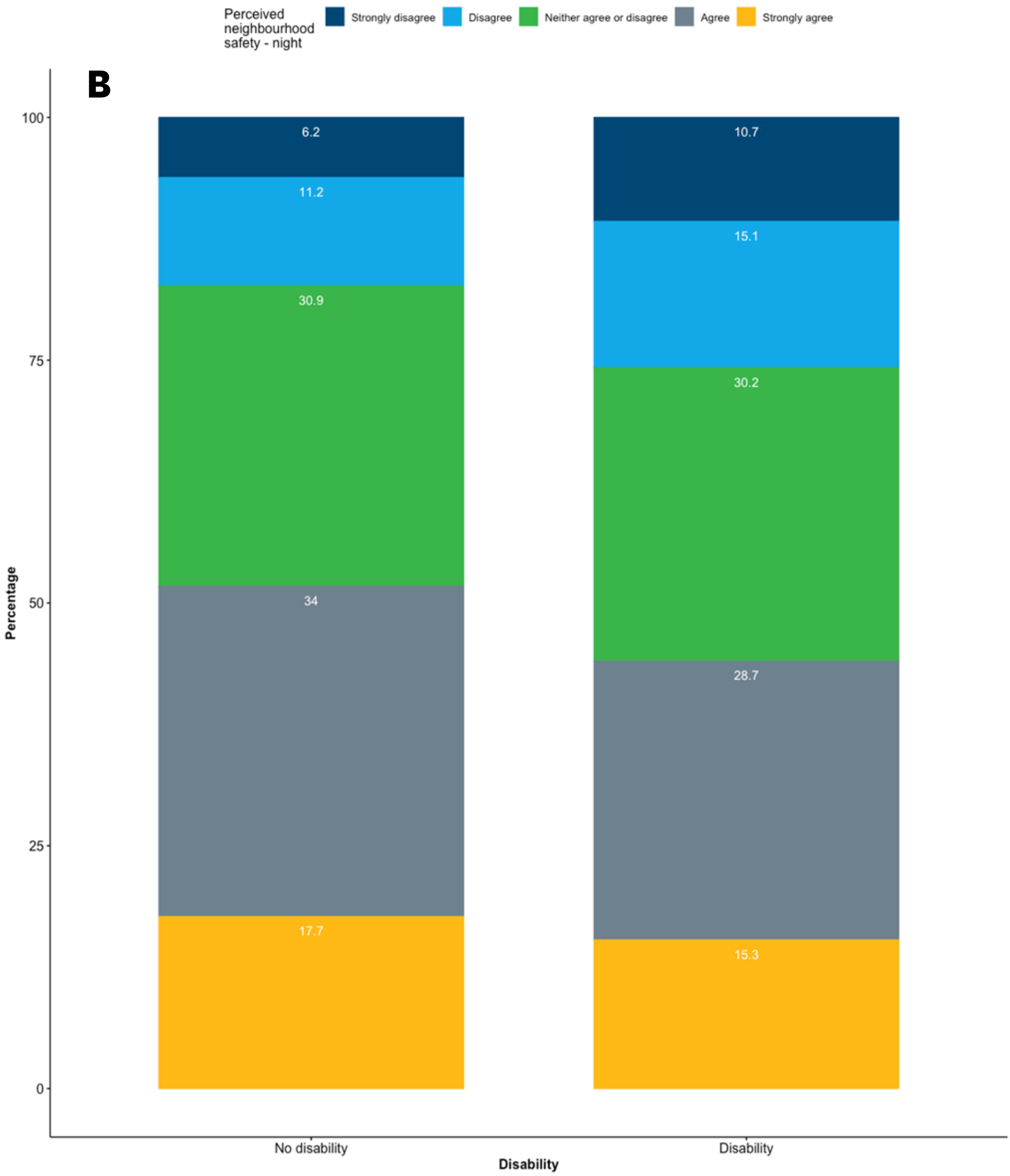


Figure 13B. Feeling safe walking and playing in their neighbourhood by night, by young person disability (*n* = 4419)

The findings in this section indicate that disabled young people do not feel as safe in their neighbourhoods as those without a disability. These differences may be explained by socioeconomic and/or neighbourhood differences. This is an area for potential future research.

## Education

Due to the complexities of education and the incongruence identified earlier in this report, when considering educational outcomes, we have included all disabled young people identified either through the WG-SS and/or by the CFM-based questions, as well as those identified as having an additional learning support need that may indicate a disability (as defined in Appendix 1.1.1). When young people with additional learning support needs were included in the definition of disability, the proportion of young people with a disability increased from 19.4% (*n* = 868/4482) to 24.5% (*n* = 1099/4482).

Details on the analytic sample used for these analyses can be found in Appendix 2.

### School engagement

School engagement (including cognitive, behavioural, and emotional engagement) gave a mean score ranging from 1-5, with higher scores equating to greater engagement (see School engagement report for more detail on this scale). The mean score of the cohort was 3.76 (median 3.79; *n* = 4421). Those with no disability had a significantly higher mean score (3.84±SD 0.66, median 3.87) than disabled young people (3.53±SD 0.71, median 3.53; Welch's F=161.19, p<.0001; Figure 14).

This finding suggests that disabled young people were less engaged at school.

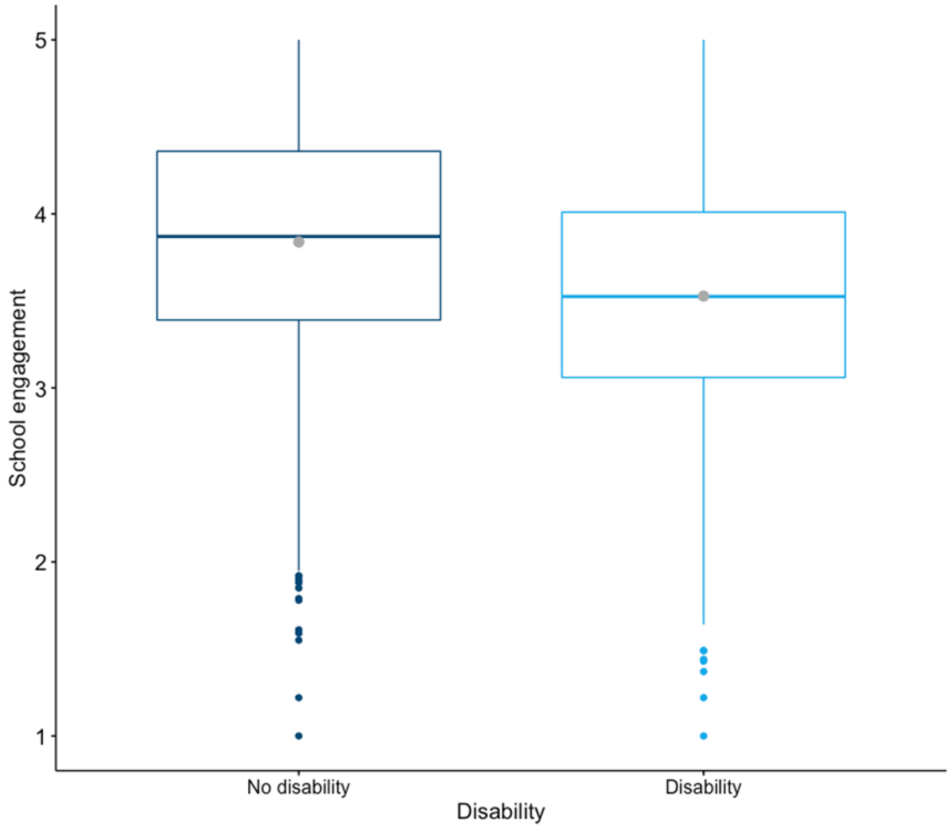


Figure 14. School engagement score of the cohort, by young person disability (*n* = 4421)

## Access to and satisfaction with disability and learning support services

Access to school services such as disability and additional learning support services in the school setting was asked of the mothers or main caregivers. Those who reported that they **had** accessed these services were then asked how effective or useful they found them. This means we **cannot** assess barriers to access for those who wanted to use these support services but for whatever reason were unable to. According to parents, just 6.3% (*n* = 266/4250) of young people had accessed disability and learning support services in the school setting. As expected, a larger proportion of disabled young people (20.5%, *n* = 219/1068) had accessed these services. However, in addition to those we identified as disabled, there were also 47 young people who had accessed disability and learning support services who had not been identified as disabled in our study.

Parents who reported that they had accessed these services were then asked if their young person had received all they needed from this service. Over half of parents (57.1%, *n* = 152/266) reported the young person had received all they needed from these services, just over a third (34.2%, *n* = 91/266) stated they received some of what they needed, and 5.3% (*n* = 14/266) said they did not receive what they needed at all. The most frequent reasons for not receiving some or all the services needed were:

- Due to COVID-19 or lockdown (44.8%, *n* = 47/105)
- The young person was not eligible (26.7%, *n* = 28/105)
- They could not get an appointment soon enough or at a suitable time (10.5%, *n* = 11/105).

For more information about COVID-19 see COVID-19 report.

## Participation in extra-curricular activities

We looked at extra-curricular activity participation in the cohort, by asking what activities the young people had regularly done in the past year. We then asked if there was an activity that they would like to do but do not or cannot do and furthermore why they have been unable to participate in this activity. A slightly greater proportion of disabled young people (34.3%, *n* = 373/1089) reported wanting to do an extra-curricular activity but were unable to, than young people with no disability (28.3%, *n* = 950/3359).

Reasons for not participating in an activity where there was a difference by disability status were:

- Lack of time (disability – 32.5%, *n* = 121/372; no disability – 38.3%, *n* = 364/950; Pearson $X^2$=3.86, p=.05).

- They thought that people might make fun of them (disability - 6.2%, *n* = 23/372; no disability - 3.2%, *n* = 30/950; Pearson $X^2$=6.36, p=.012).

Other reasons stated, that did not differ by disability status, were:

- Not being good at the activity (18.0%, *n* = 238/1322).
- Activity not being available in their neighbourhood (17.7%, *n* = 234/1322).
- The activity was too expensive (17.0%, *n* = 225/1322).

Outcome 1 of The New Zealand Disability Strategy (1) states that disabled people should be able to participate and be included in all areas of education and extra-curricular activities, and that they will have positive experiences within education. These findings suggest that just 6.3% of young people had accessed disability and learning support services in the school setting, and that nearly 40% of disabled young people who had accessed these services did not receive all the disability and learning support services that they needed at school. In contrast, access to extra-curricular activities did not seem to differ by disability status.

## 6.2. Research question 2: What proportion of young people and parents are experiencing disability at the 12-year data collection wave (DCW)?

### — Objective 1 —

*To derive and describe disability in a family setting by including mother, partner, and young person at the 12-year DCW.*

This variable included:

- All disabled young people identified using either the WG-SS and/or by the CFM-based questions (19.4%, *n* = 868/4482).
- Disabled parent included those parents (both mother/main caregiver and their partner) who self-identified that they had a long-term (six months or more) disability (14.7%, *n* = 631/4293).
- A total of 29.4% (*n* = 1317/4485) of the families in the study had experienced disability; 4.1% (*n* = 182/4485) of families had both a disabled young person and either one or both mother and partner with a disability. This does not include siblings or others living in the same household.

Details on the analytic sample used for these analyses can be found in Appendix 2.

After consultation with our key stakeholders, we further derived a three-category variable that described no disability within the family (70.6%, *n* = 3165/4482), families where only the participant young person had a disability (15.3%, *n* = 686/4482), and families in which one or both parents had a long-term disability - the participant young person may also have had a disability, 14.1%, *n* = 631/4482). See Appendix 1, Section 1.1.2 - for additional details on this variable.

***"I have cool friends and family and food and a house"***

***"…I have supportive parents and a warm house to live in"***

***"Having a good community full of good family members and friends"***

At the 12-year DCW, most of our young people were living in families with two-parents (82.7%, *n* = 3686/4458), 16.8% (*n* = 748/4458) were living in solo parent families and less than 1% (0.5%, *n* = 24/4458) were living in another type of family situation. These proportions were similar for both families with no disability and those with parent(s) and young person or parent(s) with disability. However, there was a significantly higher proportion of disabled young people in households with solo parents compared to both other categories (21.7%, *n* = 148/683; Pearson $X^2$=34.20, p<.0001). Additionally, although less than 100 (2.1%, *n* = 95/4458) families were living with non-kin, there was a higher proportion of families with a disabled young person compared to the other two categories (3.4%, *n* = 23/683; Pearson $X^2$=7.36, p=.025).

No other household structure variables differed by disability. Over 500 families (11.5%, *n* = 514/4458) were living with extended family, and 9.1% (*n* = 406/4458) were living in inter-generational families. The average "bubble" size for the cohort was 4.7 (*n* = 4457, median 4.0) people per household, and this was also not different for families with and with no disability.

## — Objective 2 —

*To describe family disability by household and economic factors such as rurality, tenure, crowding, mobility, income, deprivation, and material hardship, both at the 12-year DCW and across time.*

### Household tenure and crowding

At the 12-year DCW, 82.2% of families (*n* = 3612/4396) were living in an urban setting compared to 17.8% (*n* = 784/4396) living in a rural setting. This proportion was similar for all disability categories. Household tenure however shows significantly higher proportion of families with disability (both young person and parent(s) and young person or parent(s) with disability) living in rental accommodation compared to families owning their own home (Pearson $X^2$=48.03, p<.0001; Table 4).

Table 4. Home ownership at 12-year DCW, by young person disability (*n* = 4263).

| | Ownership | Rental | Total |
|---|---|---|---|
| **No disability** | 2343 (73.0) | 651 (61.8) | 2994 (70.2) |
| **Young person** | 447 (13.9) | 207 (19.6) | 654 (15.3) |
| **Parent(s) and young person or parent(s)** | 419 (13.1) | 196 (18.6) | 615 (14.4) |
| **Total** | 3209 (75.3) | 1054 (24.7) | 4263 |

Note: Percentages in brackets (%). These are column percentages for home ownership by disability but row percentages for total home ownership across the cohort.

Using the Canadian Crowding Index (CCI)[†] our data also shows a significantly higher proportion of families with a young person with disability living in crowded housing (young person – 14.2%, *n* = 97/682; no disability – 10.0%, *n* = 313/3140; Pearson $X^2$=10.59, p=.005). The proportion of families with parent(s) and a young person or parent(s) with disability was similar to families with no disability.

When looking at housing stability we have assessed number of moves since the participants were eight years old. At the 12-year DCW over half the young people had not moved since we last interviewed them (54.0%, *n* = 2344/4342), and a quarter had moved only once (25.5%, *n* = 1109/4342). The proportion of families with no disability that moved twice (10.9%, *n* = 332/3050) was lower than for both those families with a disabled young person at 13.5% (*n* = 90/666) and those with parent(s) and young person or parent(s) with a disability at 8.6% (*n* = 54/626). When we looked at the proportions of more frequent moves (three plus moves) there is a higher proportion both of families with a disabled Young person and for those with disabled parent(s) and young person or parent(s)

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[†] For more information on the derivation of the CCI using the 12-year data see Lai, H., & Miller, S. (2023). *Technical document for Canadian Crowding Index: 12-year Data Collection Waves.* Auckland: Growing Up in New Zealand, University of Auckland.

compared to those with no disability (no disability – 8.8%, *n* = 269/3050; young person – 10.8%, *n* = 72/666; Parent(s) and young person or parent(s) with disability – 11.5%, *n* = 72/626; Figure 15).

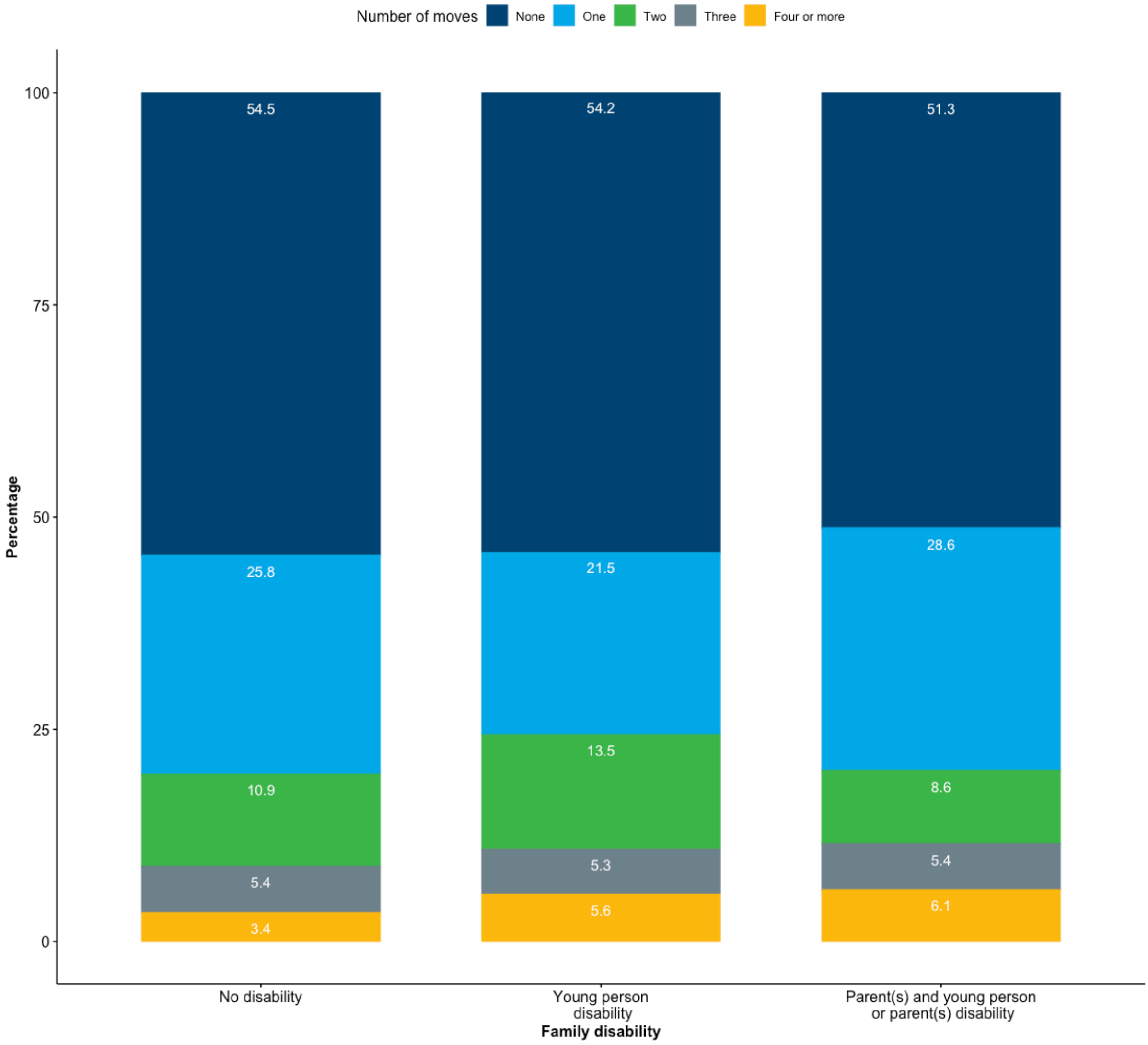

Figure 15. Number of house moves from 8-year to 12-year DCW, by young person disability (*n* = 4342)

## Household income

Families with disability (both young person, and parent(s) and young person or parent(s)) had a significantly lower annual equivalised household income than those with no disability (young person - $55,611.04±SD 32,885.65, median $52,083.75, parent(s) and young person or parent(s) - $53,629.37±SD 32,383.51, median $48,077.31, no disability - $62,657.54±SD 32,661.65, median $59,524.29; Welch's F=23.44, p<.0001; Figure 16).

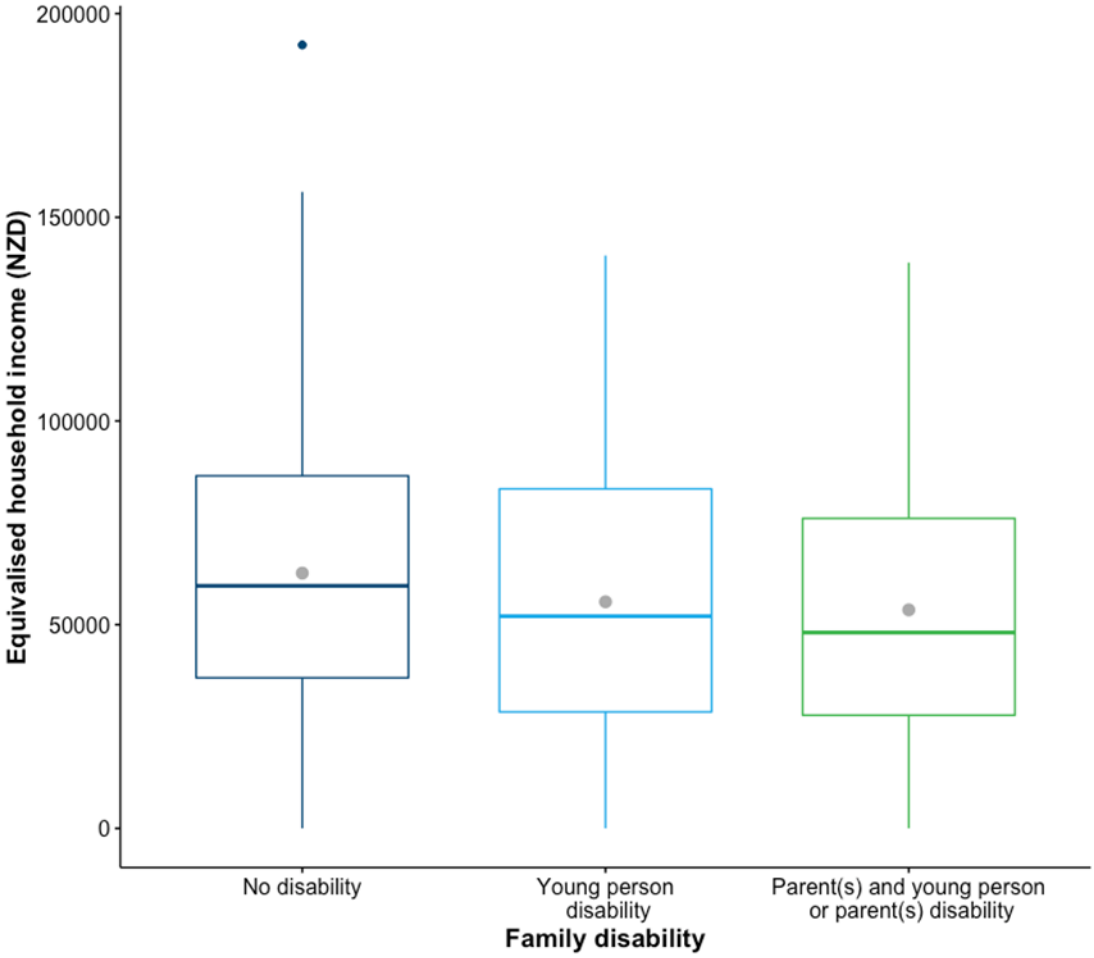

Figure 16. Annual equivalised household income (OECD) of the cohort, by family disability (*n* = 3623)

## Economic wellbeing (deprivation and hardship)

We used NZ area level deprivation quintiles (NZDEP18) to assess economic wellbeing in the cohort. At the 12-year DCW, a larger proportion of families with disability (both young person; and parent(s) and young person or parent(s)) were living in households in the most deprived (quintile 5) areas (young person 23.7%, parent(s) and young person or parent(s) 19.8%, no disability 15.7%; p<.0001; Pearson $X^2$=33.48; Figure 17).

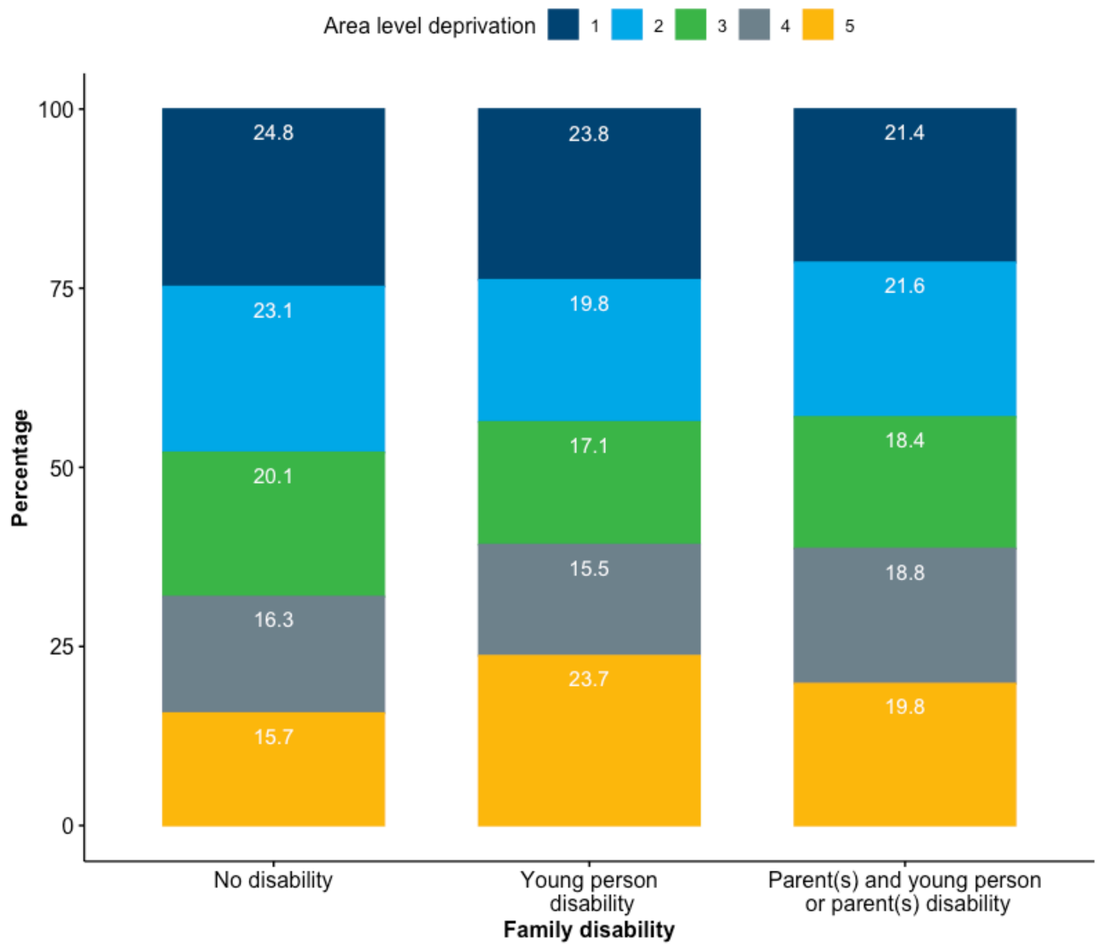

Figure 17. NZDEP18 quintile at the 12-year DCW, by family disability

Longitudinally, we assessed families who lived high deprivation (quintile 5) at each of the DCWs. This gave a score across time of 0-6, where 0 indicated never having lived in a high deprivation area at any DCW, 6 indicates families who lived in high deprivation areas at every DCW. Results showed that over half the families with no disability (56.9%, *n* = 1542/2709) had never lived in high deprivation areas, compared to 47.0% (*n* = 272/579) of families with a young person with disability, and 49.5% (*n* = 273/552) of families with parent(s) and young person, or parent(s) with disability (Figure 18).

The proportion of families who had lived in high deprivation areas at half of the DCWs (score of 3) was larger in families with a young person with a disability (8.8%, *n* = 51/579) compared to both families with no disability (6.3%, *n* = 170/2709) and families with parent(s) and young person, or parent(s) with disability (8.0%, *n* = 44/552). A larger proportion of families with a young person with a disability (13.1%, *n* = 76/579) lived in high deprivation areas at every DCW (score of 6) compared to both families with no disability (8.1%, *n* = 219/2709) and those with parent(s) and young person, or parent(s) with a disability (8.9%, *n* = 49/552).

We also assessed this variable as a continuous sum score which gave a mean score for each disability category. Results showed that families with no disability had the lowest mean score for experiencing high deprivation (mean = 1.39±SD 2.0, median 0.0). This was significantly lower (Welch's F=13.31, p<.0001) than both families with a young person with disability (mean = 1.87±SD 2.21, median 1.0) and those with parent(s) and young person or parent(s) with disability (mean = 1.65±SD 2.09, median 1.0).

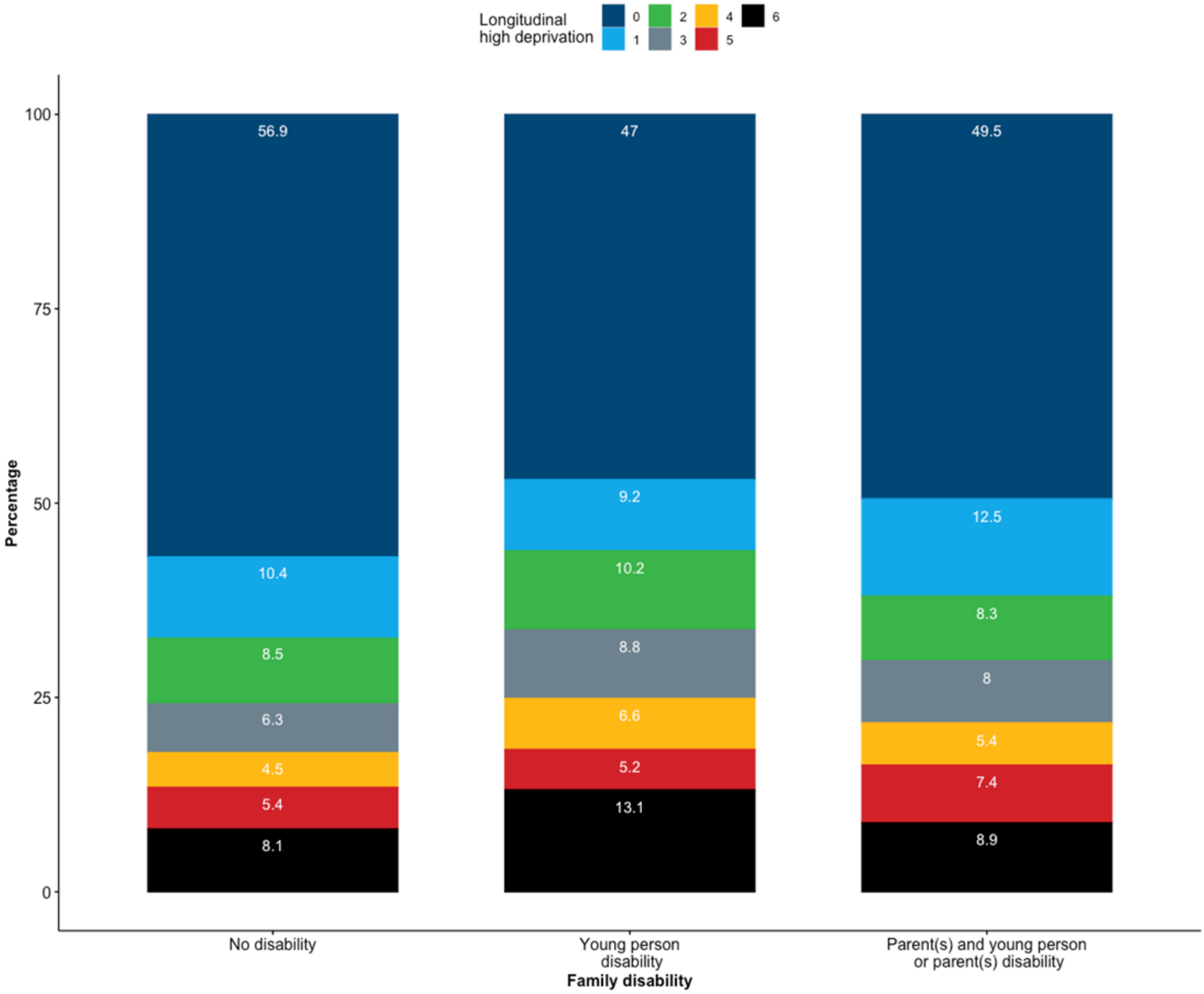

Figure 18. Proportion of families experiencing high deprivation summed across the DCWs, by family disability (*n* = 3840)

Material hardship was investigated at the 12-year DCW using a series of questions and categorised into families who had experienced no/little material hardship, material hardship, and severe material hardship (see Material Hardship report). Over 90% of families with no disability experienced no/little material hardship (92.9%, *n* = 2791/3003). The proportion of families who experienced either material hardship or severe material hardship for either family disability category was greater than for those with no disability (no disability 7.1%, *n* = 213/3003, young person disability 14.7%, *n* = 97/662, parent(s) and young person, or parent(s) disability 15.8%, *n* = 98/621; Pearson $X^2$=82.15, p<.0001; Figure 19).

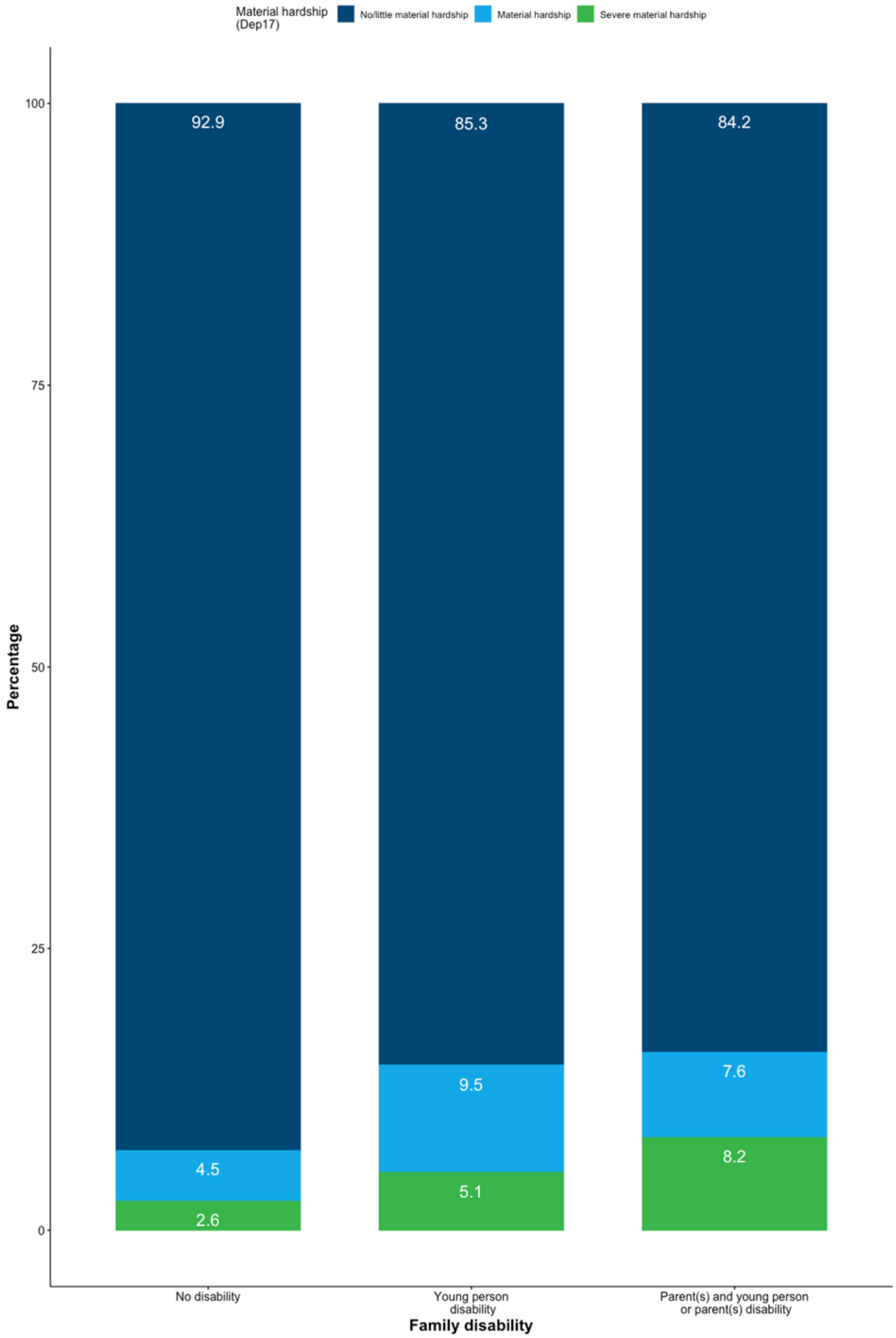

Figure 19. Material hardship at the 12-year DCW, by family disability

To explore changes in material hardship across the DCWs for families with disability, we used the sequence state cluster analysis as described in the Material Hardship report. Results show that there were significantly more families in either family disability category both in increasing and persistent hardship across time compared to families with no disability (Pearson $X^2$=120.79, p<.0001; Figure 20).

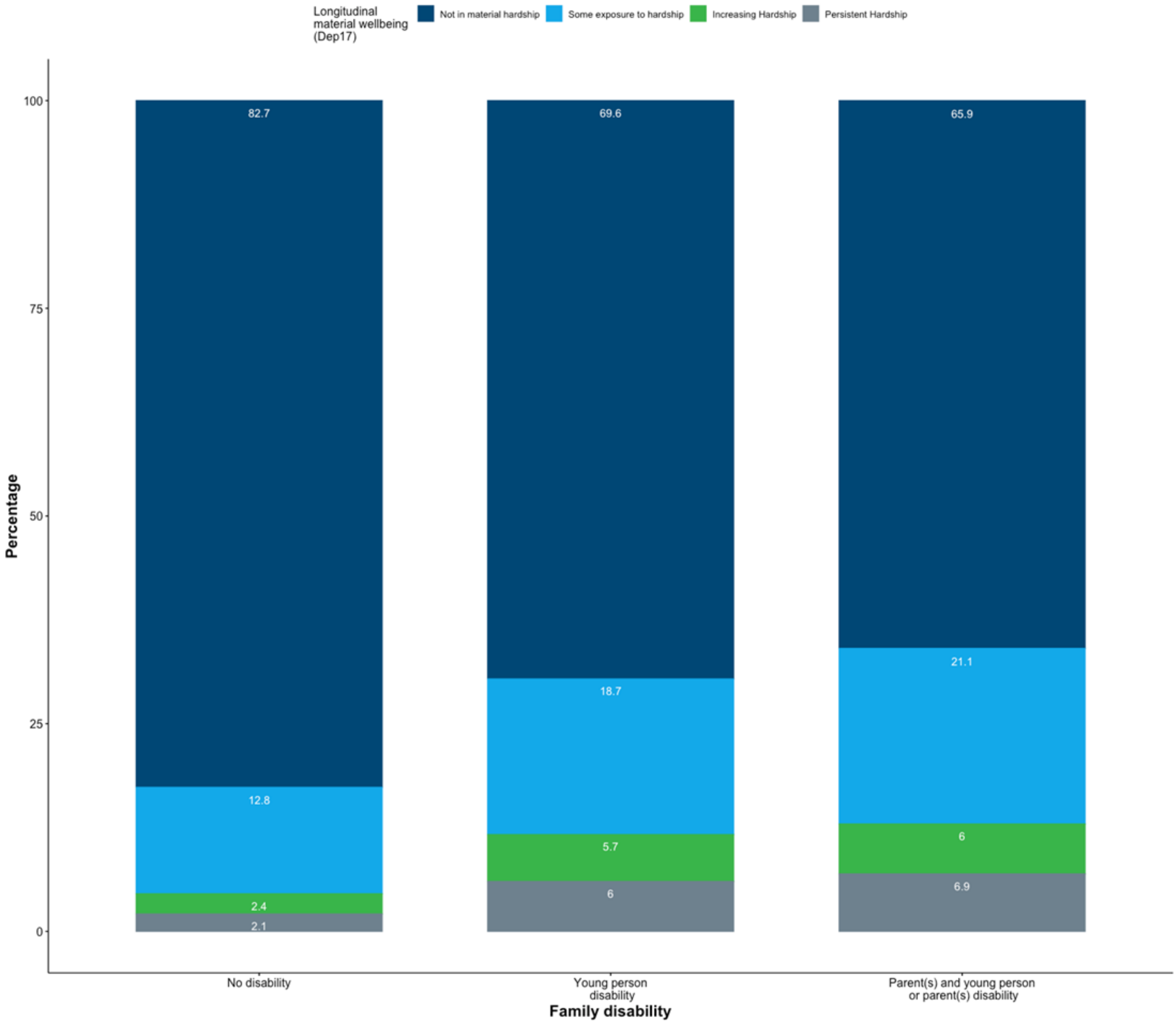

Figure 20. Longitudinal material hardship, by family disability (*n* = 3739)

Outcome 2 of the New Zealand Disability Strategy (1) highlights that disabled people and their whānau should have equitable levels of income and experience economic security. The findings in this report highlight that family's with a disabled young person or parents are more likely to experience persistent levels of material hardship and lower household incomes.

# 7. Relevance for policy and practice

This report has examined outcomes for disabled young people in NZ aged 12 years. In line with previous research findings (7-9), we found that disabled young people tended to have poorer outcomes in health, wellbeing, education, relationships, and sense of safety. For NZ to achieve its vision to be a non-disabling society (1), it is important that disabled young people's experiences remain a priority across government groups, including in the implementation of the Child and Youth Wellbeing Strategy (10).

### *Self-reported disability differed by gender, ethnic group, and area level deprivation*

This report highlights inequities between Indigenous and non-Indigenous disabled young people, with 13.0% of rangatahi Māori experiencing disability compared with 8.0% of Europeans. A report commissioned by the Waitangi Tribunal (7), found that failing to identify and respond to the needs of tāngata whaikaha Māori (Māori people with a lived experience of disability) was in breach of Te Tiriti o Waitangi. *GUiNZ* empowers the Government to better meet the needs of tāngata whaikaha by providing novel and detailed information about experiences of disability at the individual and whānau level. As recommended by the Waitangi Tribunal (7), it is important to seek to understand the intersectionality in those who identify as Māori and disabled. To address these inequities, there is a call for accountability measures to ensure equitable outcomes for Māori both with and without disability, and to develop culturally responsive approaches to health and wellbeing.

Like previous research (6, 11), this report found that a significant proportion of disabled young people were also transgender, non-binary or unsure of their gender. Responsiveness to Te Tiriti o Waitangi requires recognising that takatāpuitanga (being free of strict notion of gender identity) is a taonga, and takatāpui whaikaha Māori are likely to be over-represented in this group (11-12). Although we have not explored intersectionality within the data, the Youth2000 report on intersectionality highlighted that greater disparities exist in groups that identify within multiple minority groups (11). It is vital that health services for disabled young people and their whānau are welcoming of transgender and non-binary young people. For this to occur, health workforce training must include upskilling to support practitioners to meet the needs of transgender and non-binary young people and their whānau, who may be more likely to require health services due to their disabilities.

### *Disabled young people reported poorer health and wellbeing outcomes*

The NZ Disability Strategy (1) highlights a need for disabled people to have equitable access to healthcare services are inclusive and responsive. This report found that disabled young people (at aged 12) experienced worse general health and mental health outcomes compared to those with no disability. In alignment with strategic documents designed to focus on changing the inequities within the health and wellbeing domain, specifically relating to health outcomes and access to health services, we recommend urgent action. For example, Te Pae Tata (the Interim NZ Health Plan 2022) (13) sets out disabled people's health and wellbeing as a priority focus and highlights the importance of the development of the Health of Disabled People Strategy (14).

### ***Disabled young people reported poorer relationships with their peers and parents and were less satisfied with their parents' involvement in their lives***

Ensuring safe and inclusive school environments for disabled young people may facilitate more trusting and communicative relationships with their peers. One way of building more inclusive school environments for disabled young people is through initiatives to prevent and respond to bullying in schools – outlined as an action in the Child and Youth Wellbeing Strategy (10). The Statement of National Education and Learning Priorities (15) also includes reducing barriers to education for disabled learners/ākonga as an objective.

Disabled young people also reported less trusting and communicative relationships with their parents and less satisfaction with the degree to which their parents are involved in their lives. Policies that provide additional support for parents could include, greater financial assistance, the alleviation of some caregiving responsibilities, and guidance for parenting disabled young people. Further investigation into the determinants of disabled young people's poorer relationships with parents could help to identify the specific areas where the parents and whānau require greater support.

### ***Disabled young people felt less safe in their neighbourhood and had lower engagement at school than young people without a disability***

More support is needed to ensure young people with disabilities feel safe in their communities. This includes creating spaces that are inclusive and accessible. Young people with disabilities identify such spaces as critical to their wellbeing (16).

Increasing the support for disabled young people within schools would not only have benefits for education outcomes but may also have an indirect effect on the health, wellbeing, and economic status of their whānau. That is, as families are better supported, they have a greater capacity to create supportive homes and environments.

The Learning Support Action Plan (17) sets out to address some of these challenges by focusing on screening to identify young people with additional learning support needs and provide supports responsive to those needs. Initiatives such as these will be key to successfully achieving the education-related outcomes set out in the New Zealand Disability Strategy (1). Furthermore, learning support services in schools and other programmes must recognise and respond to the increased need to be culturally inclusive of rainbow young people and their whānau.

***A greater proportion of families with disability were in single parent homes, lived with poorer housing quality, experienced greater residential instability, and had more persistent experiences of deprivation and hardship***

More needs to be done to address the inequities experienced by young people and their families to ensure that they experience financial stability and are supported in ways that meet individual needs. The Child Poverty Reduction Act 2018 and the Children's Amendment Act 2018 were established to ensure that child poverty is a focus across the New Zealand Government (18). There are several actions and initiatives currently underway within government to ensure that these disparities are reduced (10), such as 'Ka Ora, Ka Ako', the implementation of the Equity Index in schools, and the implementation of Healthy Homes Standards.

There is a need to take a holistic view of these issues, such as through promoting the actions and priorities outlined in the Child and Youth Wellbeing Strategy (9). Improvement in relation to the health, economic and social wellbeing of whānau can have a positive impact on young person's outcomes across their life.

## 8. Limitations of this study

Careful consideration is needed in the interpretation of these findings. At aged 12 the Washington Group on Disability recommend the collection of data using proxy-response to the CFM questions; however, we have clearly identified differences between how parents and young people perceive disablement, and functioning. Beyond the disparities in outcomes for disabled young people, this report has clearly demonstrated that defining and accurately describing who is disabled at aged 12 is complex and needs to be done with sensitivity and with a strong focus on the research questions being asked rather than based on perceived reporter reliability.

## 9. Future directions

There is limited research on how age influences the interpretation of questions nor how self-report alters the identification of someone with a disability. We have demonstrated that young people have different views from their parents in relation to their view of disablement, however what has not been established is which respondent more accurately represents someone with a disability. Exploring how self-report of indicators of disability change over time, and how it differs between respondents will be an important step in the evolution of the use of this tool with young people.

To further develop our current understanding of disability in NZ young people and their families we suggest future research should include more nuanced definitions of disability including those determined via questionnaires like The Washington Group / UNICEF Child Functioning Module (CFM) (complete) question set for both young person self-report and parent/main caregivers. We also suggest collecting young person self-report of disability identity. It is also important to consider the whole family or household with respect to understanding the impact of disability on young people and their families. There are many opportunities to explore these data further including methodologies that explore intersectionality, consider longitudinal impact of disability, and consider a variety of different outcomes such as bullying or acceptance.

## 9.1. Potential future projects

There were many young people who reported having a significant difficulty in one or more area of functioning, that their parents did not report. This disparity is one that needs to be investigated further to establish why these young people answered as they did, and how their perceived disablement impacts their lives.

Findings within this report also suggest disparities between Indigenous and non-Indigenous young people as well as those who identify in gender diverse groups. Further investigation is warranted to explore the intersectionality in the data and whether identifying within multiple minority groups increases the risk of disablement and/or inequity.

Other approaches for investigation could focus on methodologies that:

- provide insight into the impact of disability on families such as considering different trajectories of family structure, economic wellbeing, and housing conditions.
- explore functional areas of concern in relation to health from birth and how these change over time, with different population sub-groups, and investigate what this means for health, education, and wellbeing outcomes at 12 years old.
- consider disabled young people’s experience of discrimination, bullying, violence, inclusion, and acceptance.
- Investigate the reporting within different domains of functioning (WG-SS) and how this influences outcomes.

Finally, to assess the enablers and drivers of outcomes for those young people and their families with disability we recommend examining the factors that lead to enhanced health, wellbeing, and education outcomes among disabled young people, as well as the factors that lead to a family thriving. Gaining a deeper understanding of individual and family strengths will help ensure all disabled young people and their families can flourish.

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# 1. Appendix 1

## 1.1. Description of disability derivation

### 1.1.1. Disabled young person derivation

The Washington Group on Disability Statistics, an international organisation which has set out to coordinate the collection of disability data throughout the world, has developed several tools for the collection of disability data globally (19-20). The Washington Group / UNICEF Child Functioning Module (CFM) was designed to gather disability data for children aged 5-17 years and was designed to be answered by a primary caregiver. The CFM identifies young people with difficulties in the areas of seeing, hearing, walking or climbing stairs, remembering, concentrating, self-care, communication, learning, accepting changes in routine, controlling behaviour and making friends, and/or young people with frequent feelings of anxiety or frequent feelings of depression.

The Washington Group have designed another set of questions called the Washington Group Short Set on Functioning (WG-SS) for use with people aged five years and over, although the intention is that a knowledgeable proxy provide information on children and young people (4,21). It identifies young people with difficulties in the areas of seeing, hearing, walking or climbing stairs, remembering or concentrating, self-care, and communication (see Table 5).

The strength of the Short Set is its brevity; consisting of only six questions, it can be incorporated into non-disability-specific surveys allowing these surveys to yield disability data when they otherwise would not have. The Short Set identifies a cohort of disabled people which can then be used to investigate the survey's other variables with a disability-lens (looking for differences between those identified as disabled by the WG-SS versus those that were not disabled).

However, the Short Set's briefness means it must not be used to report disability prevalence or as a diagnostic tool (4,5). This is as it only covers a narrow range of difficulties, disabled people with impairments outside of the six specified difficulties are excluded. Therefore, the WG-SS cannot be expected to provide a genuine prevalence of disability. The Washington Group acknowledge that the Short Set's undercount of disabled people is especially apparent for young people, stating: "disability among children, due to the circumstances of child development and transition from infancy through adolescence, is not adequately covered by these questions and disability prevalence using the WG Short Set among those 5 – 17 years of age will be underestimated. In particular, children with difficulties associated with developmental or psychosocial disabilities may be missed. However, in the absence of other measures and other data collection exercises, these questions will provide an indication of child functioning in the domains covered for the population 5 – 17 years of age" (21).

To date the WG-SS has not been validated for completion by 12-year-olds as self-report however as disability is increasingly considering a social model of disability it is important to consider the views of young people themselves. To consider outcomes for disabled young people in this study it was important to take as many viewpoints as possible into consideration. For analysis *GUiNZ* included all young people who met the criteria for either the WG-SS (self-report) or the question set based on the CFM (proxy-report) as the group of young people considered "disabled" or "at risk of disablement".

### a. Young person self-report of disability - Washington Group Short Set on functioning (WG-SS)

Table 5. Washington Group Short Set of functioning (WG-SS) items.

| Question | Answer options |
|---|---|
| Do you have difficulty seeing, even if wearing glasses? | 0. No – no difficulty<br>1. Yes – some difficulty<br>2. Yes – a lot of difficulty<br>3. Cannot do at all |
| Do you have difficulty hearing, even if using a hearing aid? | |
| Do you have difficulty walking or climbing steps? | |
| Do you have difficulty remembering or concentrating? | |
| Do you have difficulty (with self-care such as) washing all over or dressing? | |
| Using your usual language, do you have difficulty communicating, for example understanding or being understood? | |

**Scoring:** The Washington Group recommends a threshold requires that individuals have "a lot of difficulty" or "cannot do at all" when undertaking at least one of the activities, in order to be identified as "disabled".

### b. Parent-report of disability - based on the Washington Child Functioning module (CFM)

This derived variable is based on questions pulled from several different items in the child-proxy questionnaire. The Washington Group CFM was designed to be completed by a proxy respondent who knows the young person well and is recommended as best practice in the literature for 12-year-olds. However, due to questionnaire time limitations we did not ask all the CFM questions as the tool recommends, and changes were made to some of the original CFM questions (see Table 6 below for more details). The CFM, compared to the WG-SS, would capture a more diverse classification of the term disability and more accurately represents the psychosocial model of disability that was recommended by policy stakeholders.

Table 6. Parent-Report Questions Based on the Washington Child Functioning Module (CFM).

| Question | Answer options |
|---|---|
| Does {NAME} have difficulty with self-care such as feeding or dressing themselves? | Anyone with a 2 or 3 in any question will be included as 'having a disability.'<br>0. No difficulty<br>1. Some difficulty<br>2. A lot of difficulty<br>3. Cannot do at all |
| When {NAME} speaks, do they have difficulty being understood by people inside of this household? | |
| When {NAME} speaks, do they have difficulty being understood by people outside of this household? | |
| Compared with children of the same age, does {NAME} have difficulty learning things? | |
| Compared with children of the same age, does {NAME} have difficulty remembering things? | |
| Does {NAME} have difficulty concentrating on an activity that they enjoy doing? | |
| Does {NAME} have difficulty accepting changes in their routine? | |
| Compared with children of the same age, does {NAME} have difficulty controlling their behaviour? | |
| What is the reason that {NAME} has been identified as having a Learning Support Need, disability, or as gifted and/or talented? - Hearing impairment | No/Yes |
| What is the reason that {NAME} has been identified as having a Learning Support Need, disability, or as gifted and/or talented? - Vision impairment | No/Yes |
| What is the reason that {NAME} has been identified as having a Learning Support Need, disability, or as gifted and/or talented? - Physical disability | No/Yes |
| Has {NAME} ever been diagnosed by a doctor with any of the following? - Anxiety and/or depression | No/Yes |
| Making friends | Excluded |

***Limitations to note:*** The CFM is recommended by the Washington Group, the World Health Organisation (WHO) and UNICEF as the appropriate measure to use with 5–17-year-olds, to be completed by a significant adult in the young person's life (5). Whilst the Washington Group recommend all items are asked as a scale, for brevity only eight of the questions were asked on a scale. For the **seeing, hearing and walking** domains, the original CFM questions – which ask about the level of difficulty performing these activities (as is done in the WG-SS) – were replaced with yes/no binary questions on learning support needs related to disabilities in those three domains. Furthermore, **anxiety** and **depression** which are separate components in the Washington CFM, were combined and *GUiNZ* asked about a diagnosis of anxiety and/or depression. This is different to the original CFM which does not use the word "diagnosis" and instead asks about the persistence of significant feelings of anxiety or depression. Finally, the **making friends** question has been excluded from the scale derivation as, due to questionnaire time constraints, was not asked of the parent or main caregiver.

### c. Parent-report of learning support needs

Asked of the main caregiver/parent: Has {NAME} been identified as having a learning support need, disability, or as gifted and/or talented? For those that answered YES, the subsequent question was: What is the reason that {NAME} has been identified as having a learning support need, disability, or as gifted and/or talented? The response options were non-exclusive options (see Table 7). In consultation with our policy stakeholders only those highlighted with an asterisk (*) in the table below were deemed relevant to this report when considering learning support needs and young people at risk of disablement.

Table 7. Learning support needs response options.

**Learning support needs (parent-report)**

1. Hearing impairment *
2. Vision impairment *
3. Physical disability *
4. Speech or language impairment *
5. Learning disability/intellectual disability *
6. Specific learning disability (literacy) – previously known as dyslexia *
7. Specific learning disability (numeracy) – previously known as dyscalculia *
8. Emotional or behavioural problems *

**Learning support needs (parent-report)**

9. Gifted and/or talented—Intellectual ability (exceptional ability in one or more learning area)
10. Gifted and/or talented—Other ability (e.g., culture-specific, creativity, visual and performing arts, social/leadership, physical/sport)
11. Poor understanding of English/ESL
12. Autism Spectrum Disorder *
13. Illness *
14. Attention Deficit Hyperactivity Disorder (ADHD) *
15. Extra subject specific support needed

**Added after upcoding of free text responses**

16. APD – Auditory Processing Disorder *
17. Dysgraphia *
18. Dyspraxia also known as Developmental Coordination Disorder *

### 1.1.2. Young person and parent disability derivation

Family disability is derived using the WG-SS (self-reported by the young person) and questions based on the CFM (answered by the parent) (see Appendix 1: Section 1.1.1 for definition) for young person score, and the mother/main caregiver's partner long-term disability question asked at the 12-year data collection wave (Table 8). We then created a three-category variable: No disability, Young person disability and, Mother/main caregiver and/or partner disability (here termed Parent(s) and young person, or parent(s) with disability. Note, if we were missing disability information for mother/main caregiver or partner but had information on young person disability, these participants were included in the young person disability category, but we recognise we will be misclassifying some families where either mother/main caregiver or partner may also have a disability.

An additional limitation of this variable is that we only have the data to assess disability for the participant young person and their parent(s), not extended family who may live with the family or siblings who may also have a disability.

Table 8. Mother or main caregiver and mother's partner long-term disability question.

| Question | Answer options |
|---|---|
| Do you currently have a disability that is long-term (lasting 6 months or more)? | Yes/No/Prefer not to say |

# 2. Appendix 2

## 2.1. Analytics sample

To ensure the results were the most relevant to the NZ context, only participants who reported that they were living in Aotearoa at the time of the survey were included in the analysis. Those who did not select which country they were living in (i.e., a NA response) were not included in the analytic sample.

From the participants in New Zealand (*n* = 4500; see Methodology report for more details), a total of 4447 (98.8%) informed the WG-SS questions, 4263 (94.7%) informed the CFM-based questions, 4482 (99.6%) informed the definition of young person disability when the combined WG-SS/CFM-based questions were utilised for outcomes, including for the questions related to education outcomes. For family disability a total of 4485 (99.6%) of families had available data to be included. We have performed no data imputation for disability variables. For imputation methods used in material hardship variables see Material Hardship report - Supplementary Material.

# 3. Appendix 3

## 3.1. Description of specific tools used for this report

### Quality of life (QoL): KIDSCREEN-10

This tool is suitable for all children and teenagers aged from eight to 18 years. It provides a generic measure of quality of life that is related to children's health. It was developed within a large three-year European project "Screening and Promotion for Health-related Quality of Life in Children and Adolescents - A European Public Health Perspective" and found to be related to the health status of the participants. As the participants resided in several different nations, this has enabled the development of a tool that is linguistically suited to use in multiple countries. The KIDCREEN-10 version (22-25) only takes five minutes to complete (see Table 9). The items of the KIDSCREEN-10 instrument can be scored as Rasch scales as they fulfil the assumption of the Rasch model (unidimensionality, homogeneity of items and persons, sufficiency of the sum score) (see Table 10).

Instructions for scoring include:

- Recode negatively formulated items:
    - Have you felt sad?
    - Have you felt lonely?
- Sum up item scores (only use data from people with complete data).
- Transform scale raw score into Rasch person parameter (PP) estimates and T values.

  - The PPs are transformed into values with a mean of 50 and SD of approximately 10.
- A low score indicates poor health QoL, and higher values indicate better QoL.
- Categories of low, average, and high QoL are derived for each participant using plus or minus half a standard deviation from the mean T score.

Table 9. KIDSCREEN-10 Quality of Life Questions.

| Question | Answer options |
|---|---|
| Have you felt fit and well? | 0. Not at all<br>1. Slightly<br>2. Moderately<br>3. Very<br>4. Extremely |
| Have you got on well at school? | |
| Have you been able to pay attention? | |
| Have you felt full of energy? | |
| Have you felt sad? | |
| Have you felt lonely? | |
| Have you had enough time for yourself? | |
| Have you been able to do the things that you want to do in your free time? | |
| Have your parent(s) treated you fairly? | |
| Have you had fun with your friends? | |

**Scoring:** QoL KIDSCREEN-10 is as follows.

Table 10. Scoring for KIDSCREEN-10

| Question | Not at all | Slightly | Moderately | Very | Extremely |
|---|---|---|---|---|---|
| Have you felt fit and well? | 0 | 1 | 2 | 3 | 4 |
| Have you got on well at school? | 0 | 1 | 2 | 3 | 4 |
| Have you been able to pay attention? | 0 | 1 | 2 | 3 | 4 |
| Have you felt full of energy? | 0 | 1 | 2 | 3 | 4 |
| Have you felt sad? * | 4 | 3 | 2 | 1 | 0 |
| Have you felt lonely? * | 4 | 3 | 2 | 1 | 0 |
| Have you had enough time for yourself? | 0 | 1 | 2 | 3 | 4 |
| Have you been able to do the things that you want to do in your free time? | 0 | 1 | 2 | 3 | 4 |
| Have your parent(s) treated you fairly? | 0 | 1 | 2 | 3 | 4 |
| Have you had fun with your friends? | 0 | 1 | 2 | 3 | 4 |

**reverse-coded items*

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